PARENTS' PERCEPTIONS OF THEIR EXPERIENCES OF
CARING FOR AN INFANT OR TODDLER UNDER
THREE YEARS OF AGE WITH INSULIN DEPENDENT DIABETES MELLITUS

by

DOREEN LILLWALL HATTON
B.S.N., The University of British Columbia, 1987

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING
IN THE FACULTY OF GRADUATE STUDIES
(School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

October 1992
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Department of **Nursing/Applied Science**

The University of British Columbia
Vancouver, Canada

Date **14th October 1992**
Abstract

Parent's Perceptions of the Experiences of Caring for an
Infant or Toddler under Three years with Insulin Dependent Diabetes Mellitus

The purpose of this phenomenological study was to explore and describe the lived experience of parents who were caring for a child under three years with diabetes, and to gain insight into this experience from the parents' perspective. The objectives of the study were to gain knowledge and understanding of the parents' needs and concerns related to caring for their child so that appropriate support and services can be planned, developed and implemented for this unique and growing population over the long-term.

A purposive sample of eight, two-parent families with diabetic infants or toddlers were selected according to the characteristics and knowledge each possessed. Data were collected through a series of fourteen indepth, minimally-structured, audiotaped interviews conducted over a five-month period. Tapes were transcribed verbatim and the data subjected to phenomenological analysis. Constant comparative analysis was employed throughout the data collection process to permit analyzed material to guide construction of the parents' accounts.

The parents described three distinct phases of their experience: the diagnosis of diabetes and the child's admission to hospital, adjusting to caring for the young child at home, and incorporating the child's diabetic management regimen into family life over the long-term. Each phase was linked to a timeframe and organized into major conceptual categories and themes constructed from the parents' accounts.

Findings revealed that parents experience inordinate amounts of stress that appear to be exacerbated by the child's young age, the all-pervading nature of diabetes, the lability of the child's condition, and the demands and fears associated with the complex daily management regimen. Parents
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Talked at length about their emotional reactions to these multiple stressors, and also described the coping strategies they used to handle their situation throughout the experience.

While some conclusions of this study confirmed findings of other studies related to caring for a child with diabetes, other conclusions revealed entirely new findings. Problems associated with multiple losses for parents and child, significant findings specific to developmental issues resulting from the young age of the child at diagnosis, the major role played by fathers in sharing responsibility for care of these children, and the frustrations of coping with the labile and unpredictable nature of the young child's diabetes, appeared particularly relevant to this unique population.

Implications for nursing practice include the provision of educational and respite care services, the provision of empathy and support, and empowerment of parents by assisting families with adaptation and stress reduction. Implications for nursing and technological research are in the realm of studies to further the understanding of the needs of these young children and their parents, and in the development of non-invasive procedures to reduce the complexity of the daily management regimen.
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ACKNOWLEDGEMENTS

I wish to extend sincere thanks and appreciation to the members of my thesis committee, Professors Connie Canam and Sally Thorne, for their enthusiasm, support and encouragement, their expertise in guiding me through the research process, and their valuable suggestions for clarifying and improving the text. Also, my gratitude to Professor Anne Marie Hughes for providing significant feedback on the final manuscript. These three professors not only encouraged me during this research project, but also profoundly influenced my thinking during other academic phases of the Master's Program.

I also extend thanks to Dr. W.J. Tze and members of the Diabetes Management Team at B.C.'s Children's Hospital for encouraging me to pursue this research, and to Judith MacDonald for her support and interest in the research process.

On a practical point, I acknowledge the skill, patience and tenacity of Garth Spencer and Clare Maycock for typing and layout of the text.

Finally, I am deeply indebted to my family. To my children, each of whom has grown, matured and pursued their own academic quests while simultaneously supporting mine. And to my husband, John, I offer profound thanks and appreciation for his constant support, encouragement, and patience throughout my university studies. His interest in my work and the innumerable hours spent reading and editing my manuscripts deserve special acknowledgement.

For the families who gave me inspiration, I submit the following dedication.
This thesis is dedicated to the eight families who so generously and willingly gave of their time to participate in this study. The enthusiasm and warm hospitality shown by these busy parents touched me deeply. Their frankness and willingness to express personal feelings about a particularly stressful time in their lives has contributed significantly to my understanding of the complex and multifaceted experience of caring for such young children with diabetes, and has provided insight into ways nurses can best intervene to support and work effectively with these families.
CHAPTER ONE

Introduction

The Rationale for Study

This study was designed to explore parents’ perceptions of their day-to-day lived experience of caring for an infant or toddler under three years of age with insulin dependent diabetes mellitus. Impetus for the study was initiated by questions and concerns and a need for understanding that arose from observations made by the researcher during clinical nursing practice. While working with families of children newly diagnosed with diabetes, and providing support, education and advocacy for these families in the emergency, inpatient and ambulatory clinic settings, the researcher became implicitly aware of the widespread implications and pervasive influence that this life-long illness could have on the day-to-day life of the child and each family member.

Over a five-year period of involvement, collaboration, interaction and follow-up with these families, the researcher developed a deeper understanding of the complex, multi-faceted and often stressful daily experiences described by children and adolescents with diabetes and their parents. As a member of the diabetes management team involved in developing educational programs, support groups and community outreach programs to meet the needs of these families, a broader insight into the overall experience of living with a child with diabetes was achieved. However, ongoing dialogue with family members during this clinical experience also made the researcher cognizant of some of the unique management problems and special needs of an emerging and increasing sub-group of parents caring for infants and toddlers diagnosed with insulin dependent diabetes mellitus. During close interaction with these parents, questions and concerns arose to indicate that some of the experiences of caring for such young children with diabetes were quite different from the experiences of caring for older children or adolescents. Observation of these families also provided striking evidence to suggest that the impact of
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diabetes on the daily lives of these infants and toddlers and their parents was little understood by health care professionals, extended family members, or the community. Consequently, the need for a study to provide increased knowledge and understanding for health care practitioners involved in the care and support of these young clients and their families was indicated. This need was supported in the literature, and will be discussed later in this chapter under background to the problem. Comments made by parents that lent credence to the study were summed up by the distraught mother of an eleven-month-old infant when she returned to the ambulatory clinic several weeks after her young son was diagnosed. When asked how she was feeling and how she was coping with her infant's diabetes management at home the mother replied:

"It's so hard. No one could possibly believe how hard and how totally overwhelming it is. You see no one else really understands. Not our relatives, not anyone. Unless you've been through this, lived with it day by day how can you possibly perceive the problems or begin to understand!

In the beginning, of course, we were in shock and totally devastated. We performed just like robots. We didn't really understand what diabetes was all about, but knew we had to learn all about needles and blood tests in order to take our baby home from the hospital. Once we got home I began to think I cannot manage this, how can I change my whole life to accommodate all these pokes, all these injections and all these meals for such a little child. You see I was just getting used to being a new mother and to caring for a baby, I wasn't prepared at all for this extra burden. And I think of diabetes like this heavy stone around our necks, it's always there, it never goes away and it takes the joy and pleasure out of being a parent. Sometimes I feel so inadequate, so inexperienced, so frustrated and afraid. I'm still afraid of the needles, and he's so small he doesn't understand. You can't explain to him, and when he struggles and cries and I have to poke him I want to say, no, that's enough, no more, and each time he cries, I cry too.

I also panic if he won't eat, I'm so afraid his blood sugar will fall too low, but how do you persuade an eleven-month-old to eat if he doesn't want to? It's so frustrating.

I think for a parent it's an awesome responsibility because such a little child is totally dependent on you for his very existence, his very life on a day-to-day basis, twenty four hours of every day. Because he is so young we have to think for him, feel for him, anticipate for him and judge his actions and his moods. Sometimes I don't know whether he is irritable because he's just tired and needs a nap like a normal infant, or whether he's irritable because his blood sugar is too high or too low. We need to constantly monitor him, check him, fear for him and protect him because he's too little to tell us how he feels.

No one really understands, not our family or friends, they see what we need to do for our baby, the needles, the constant monitoring and they back right off, they cannot handle it, so we are usually left to manage alone. It's very hard, and what we really need is someone to listen, someone to know what we are really going through, someone who truly understands."
After listening to the sentiments expressed by this mother and other parents of infants and toddlers with diabetes, the researcher decided to further explore the meaning of the experience of caring for these young children from the parents’ perspective. An exploration of the background to the problem revealed a lack of information on the subject, and a need was expressed by other health care practitioners for studies to identify the perceptions of parents surrounding their experience of managing an infant or toddler with diabetes.

Background to the Problem

Diabetes in children is recognized by researchers and health care practitioners as a lifelong illness requiring a complicated daily management regimen in order to maintain good diabetic control, achieve normal growth and development, prevent complications, and promote and sustain optimal level of functioning for the child (Betschart, 1988; Brink, 1987; Hatton, 1988; Hunt & Alojado, 1989; Krall & Beaser, 1989; and Tze, 1989b). For the past decade, there has been a significant increase in the incidence of insulin dependent diabetes mellitus in infants and toddlers under the age of three years (Tze, 1989b). These young children present with clinical characteristics and special needs which are quite different from those of older children or adolescents. However, comprehensive information on the subject is lacking and only a few studies deal with particular problems of this special age group (Tze, 1989b). Therefore, it is important that nurses and other health care practitioners involved in the care of these young clients should understand any unique management problems experienced by both the child and his or her parents, so that optimal management regimens can be developed (Tze, 1989a).

Because the full responsibility for the day-to-day care of any child with diabetes ultimately lies with the parent or primary caregiver, it is expected that these significant individuals have the potential to achieve an appropriate standard of competence that ensures the provision of safe, effective care and management for their diabetic child. It is also a belief of many health care professionals that, in order to
achieve and sustain good diabetic control for a child with diabetes, parents or primary caregivers must collaborate with health care professionals, share experiences, and function as equal, essential participating members of the health care team (Metabolic Investigation Unit, 1986).

Research studies have shown that the demands and stresses of the diabetic management regimen on parents of children with diabetes can contribute to neurotic behaviour in parents that may require professional intervention to overcome (Betschart, 1988; Tze, 1989a). It is also acknowledged that a parent’s or primary caregiver’s ability to adapt to these new responsibilities depends on that individual’s values, beliefs, past life experiences and ways of perceiving the situation (Anderson, Elfert & Lai, 1989; Hayes & Knox, 1984). Studies have also shown that significant differences emerge when comparisons are made between the goals of medical professionals and the goals of parents in treating children with diabetes. Parents’ goals of treatment appear to be governed more by avoidance of the short-term threats of diabetes, such as hypoglycemia, whereas medical goals are more closely related to long-term management and the threat of complications. The problem of treatment failure for a child with diabetes could result from a difference in goals between medical professionals and parents, and a more effective clinical alliance would result if the goals of parents were better understood by health care professionals (Marteau, Johnston, Baum & Bloch, 1987). It has also been suggested that there is an association between the family environment, parental involvement with their children and the degree of metabolic control achieved by a child with diabetes (Standen, Hinde & Lee, 1985). Understanding any differences or similarities in individual family functioning that impact on the diabetic child’s metabolic control could provide useful directions for possible intervention programs. Consequently, it is necessary for nurses to gain knowledge and understanding of the parents’ perceptions of their experience regarding care of the child with diabetes on a day-to-day basis. In this way, nursing interventions can be responsive to the developmental, cultural, social and emotional life of both the child with diabetes and his/her caregiver.
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Children with Diabetes

Over 900 children between the ages of 3 weeks and 17 years are followed on an annual basis by the Diabetes Management Program at B.C.'s Children's Hospital. The Health Surveillance Annual Report indicated a prevalence rate of 564 children with diabetes in B.C. in 1977; this increased to 2,009 in 1982 and has continued to increase. Incidence rates for both Type I and Type II diabetes in B.C. was quoted as 150,000 adults and children in 1987 (Health Surveillance Annual Report, 1987). However, because registration is voluntary, it is predicted that these figures are minimal. The paediatric population with diabetes in B.C. in 1989 was quoted as a prevalence rate of 1/600 children, and the incidence rate at 8-16/100,000 per year is increasing (Couch, 1989, p. 57). Peak onset for insulin-dependent diabetes in children is late childhood or adolescence (Couch, 1989, p. 57). However, the recent increase in the incidence of insulin dependent diabetes in children under three years of age has been striking. From a total of 122 infants and toddlers under three who have been followed by the Diabetes Program at B.C.'s Children's Hospital over the past 17 years, 32 were diagnosed before 1979 and 90 were identified and treated between 1980 and 1989 (Tze, 1989b, p. 52). During 1990 and 1991, the incidence rate has again risen dramatically and has included infants less than one month old. Young children under three years of age present with severe ketoacidosis and dehydration, as well as markedly elevated blood sugar levels of > 40 mmol/L. During the first year following diagnosis, these infants and toddlers are more prone to develop severe hypoglycemic episodes which are often associated with convulsions. Blood sugar levels and glycosylated hemoglobin are more difficult to maintain at satisfactory levels. Erratic eating patterns, activity levels and rapid growth all compound these problems. These young clients present a major challenge to health care professionals, and the diagnosis of diabetes in this early period of life is very serious for both the affected child and his/her parents. Intensified education, nursing intervention and support for parents are critical components of management, as parents are required to perform invasive
procedures such as insulin administration and blood glucose testing on their child on a regular daily basis; and, simultaneously, have the ability to respond to results (Tze, 1989a; Tze, 1989b).

Because of the inability of these young children to communicate their own feelings and needs, the full responsibility for anticipating changes in diabetic control for the child lies with the parent or primary caregiver. These significant individuals are expected to have the knowledge and skills to anticipate any change in their child’s condition, predict patterns in blood glucose levels that could indicate the development of hypoglycemic episodes or hyperglycemia and ketonuria, plan appropriate actions to prevent such episodes, and maintain acceptable diabetic control for their child. These expectations are placed on parents and primary caregivers by health care professionals. However, the difficulties occurring both for the child and for the parents, due to the constant need for invasive procedures, have not been fully explored (Tze, 1989b), and the perceptions of parents surrounding their lived experience of caring for an infant or toddler with diabetes are largely untapped.

Thus, the study described here was designed to explore and describe the perceptions of parents surrounding their experience of caring for a young child under three years with insulin dependent diabetes mellitus. Information gained will contribute to understanding of this experience from the parents’ perspective, and provide insight for nurses and other health care professionals into how they can best intervene to provide support and education for these families over the long term.

**Conceptual Framework**

The conceptual framework chosen to guide this study was developed by Kleinman (1978a) through work in the area of cross cultural medicine. Kleinman’s studies led him to conceptualize the health care system as being comprised of three different but interacting sectors, each with their own explanatory model of health and illness. These explanatory models and their significance in providing guidance for the study will now be discussed.
Western society's view of the health care system and of illness has generally been dominated by the professional, medically orientated institutions, with a focus on scientific, biomedical and objective explanations of health and illness. However, background information on the problem identified for this study indicates that significant differences emerge when comparisons are made between the goals of medical professionals and the goals of parents in treating children with diabetes. It also acknowledges that the full responsibility for the day-to-day care of any child with diabetes ultimately lies with the parent or primary caregiver; and that the ability to adapt to these responsibilities depends on that individual's values, beliefs, past life experiences and ways of perceiving the situation (Anderson, Elfert & Lai, 1989; Hayes & Knox, 1984). Kleinman's concept of explanatory models proposes that the health care system is much more inclusive than Western society's view of the medically orientated institutions, and in fact represents a total, cultural organization of medically-relevant experiences, as well as an integrated system of social and personal perceptions, uses, and evaluations (Kleinman, 1978b, p. 414).

Kleinman asserts that "most health care systems contain three structural arenas within which sickness is experienced and reacted to" (1978a, p. 86). These are the professional (nursing, medical and other professions); popular (individual, family, social network, community), and folk (nonprofessional healers) arenas. Each domain of health care conceptualized by Kleinman is viewed as a sociocultural system with its own beliefs, values and norms, and its own explanatory model of health and illness (Anderson, 1985, p. 237). Within the context of this framework, a distinction is made between disease and illness. Disease is the malfunction or maladaptation of biological or psychological processes, whereas illness signifies the experience of disease. Illness is the way in which an individual, parent, family or social network perceives and responds to disease (Kleinman, 1978a). Therefore, illness is culturally shaped. How we perceive, experience and cope with disease is based on individual explanations specific to the social positions occupied and the meanings employed (Kleinman, 1978a, p. 86). Interactions between the nurse (professional arena) and parent or client (popular arena), are transactions between explanatory
models which differ in cognitive content, expectations and goals (Kleinman, 1978a, p. 86). Differences in explanatory models lead to varied interpretations of health and illness, and thus differing expectations and goals. Therefore, working within the framework of this model, the nurse is directed towards understanding the client’s explanatory model, and the encounter between the nurse and client (or parent) becomes one of sharing the explanatory models of the situation. Using Kleinman’s framework, Anderson (1985) explains that the nurse elicits from the client how he or she understands the situation, and then helps the client acquire knowledge and skills to cope with the situation in a way that is culturally acceptable to the client (p. 239). The phases of nurse/client interaction (exploration/negotiation, working/collaboration, and reflection/co-ordinating) (Anderson, 1985, p. 239), fit with the assumption that parents of young children with diabetes are essential, participating members of the diabetic management team.

For the purpose of this research study, the domain of inquiry is the popular arena of Kleinman’s (1978a) health care system’s explanatory models (see Figure 1). The popular arena comprises principally the family context of sickness and care, and between 70% and 90% of sickness is managed solely within this domain (Kleinman, 1978a, p. 86). This arena encompasses beliefs, choices, decisions, roles, relationships and interactions, and includes the parents’ subjective experience of their young child’s long-term illness of diabetes, and their perceptions of caring for the child and managing the required diabetic regimen.

Because many of the tasks delegated to parents of children with diabetes are those initially performed by nurses, and because nurses teach the parents the necessary skills and knowledge to manage the child’s diabetic regimen, use of Kleinman’s framework can direct nurses towards understanding that parents may view their caregiving management role in a sociocultural context different from their own.

Generally, the long-term care of the infant or toddler with diabetes becomes a negotiated, collaborative and supportive role between health care professionals and the child’s parents.
Consequently it is important for those in the professional structural arena of the health care system to acknowledge, understand and respect the parents' explanatory model, which is based on their personal experience within the popular structural arena (Kleinman, 1978a).

Fig. 1. Health care system: internal structure

Health Care Systems Model

Adapted from "Concepts and a Model for the Comparison of Medical Systems as Cultural Systems", by A. Kleinman, 1978, Social Science and Medicine, 12, p. 86.

Kleinman's conceptual framework directed the researcher to design a study which explored parents' perceptions regarding care of their infant or toddler with diabetes. Data elicited from the parents' articulated experience can contribute to a deeper understanding of the explanatory models associated with day-to-day management of these young children over the long term. The specific research problem addressed in this study is developed from the previously stated questions, concerns and needs for knowledge and understanding identified at the beginning of this chapter.
The general problem which this study addresses is the paucity of research available and subsequently the lack of knowledge about the perceptions of parents concerning their experience of caring for an infant or toddler under three years with diabetes. Over the past decade, there has been a significant increase in the incidence rate of insulin dependent diabetes in these young children. However, although previous studies show that the demands of the diabetic management regimen affect parents of diabetic children of all ages, experience with diabetes in the young child is rarely described (Tze, 1989b).

No studies are available to provide insight into the lived experience of caring for an infant or toddler with diabetes as perceived and articulated by the parents, yet a parent’s attitude towards coping, their abilities to cope with the daily management regimen, and their fears, uncertainties, acceptance or over-protectiveness can affect the growth and development of the child, and influence the lifestyle and attitude of the child towards diabetes for the rest of his/her life (Lipman, Difazio, Meers & Thompson, 1989; Tze, 1989b). Nurses have the mandate to provide parents with the knowledge and skills necessary to care for their child on a day-to-day basis. However, in order for nurses to support and work effectively with parents, they must first gain an understanding of how parents perceive these experiences and responsibilities.

Because the literature indicates that people interpret health and illness in many different ways, and that these various interpretations guide health care behaviours (Anderson et al., 1989; Kleinman, 1987a; Marteau et al., 1987; Standen et al., 1985), the purpose of this study was directed towards gathering data that would help health care professionals understand the parents’ perspective regarding caring for their child with diabetes.
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Purpose of the Study

The purpose of this study will be to explore and to describe the lived experience of parents who are caring for an infant or toddler under three years with insulin dependent diabetes, and to gain insight into an understanding of this experience from the parents’ perspective. It is anticipated that the insight and understanding gained from these parents’ articulated experience will provide data on how the nurse can best intervene to provide support and education for these parents and their children over the long term.

In order to elicit the parents’ perceptions of these often complex and multifaceted daily experiences, the following specific questions will direct this study.

Research Questions

1: What is it like for parents to have an infant or toddler under three years with insulin dependent diabetes mellitus?

2: How do parents describe their lived experience of caring for such a young child who has insulin dependent diabetes mellitus?

3: How do parents perceive the impact and effect of the daily diabetic management regimen on their child, on themselves, and on family life?

Terms which could be subject to ambiguous interpretation are defined below in order to clarify their use throughout this study.

Definitions of Terms

DIABETES: For the purpose of this study, diabetes will refer to insulin dependent diabetes mellitus, a disorder involving lack of insulin production in the beta cells of the pancreas. Children with this disorder require multiple insulin injections on a daily basis to maintain blood sugar absorption by the body for energy. They must follow a specific diabetic diet.
YOUNG CHILD: Child under three years of age. Includes infants and toddlers.

PARENT: Mother, father or guardian of the young child with diabetes.

FAMILY: For this study the family includes parent(s), the young child with diabetes, siblings and any other significant individuals living in the household.

FAMILY LIFE: The general functioning of all family members as interdependent parts of the family. Includes communication patterns, interaction patterns, activities, support systems and roles family members play.

LIVED EXPERIENCE: Day-to-day living with the young child who has diabetes. May include routines, procedures, roles, diabetic management as depicted by the parent.

DIABETIC MANAGEMENT REGIMEN: May include any procedures (e.g. insulin injections or blood glucose monitoring), or tasks (e.g. preparing a diabetic diet, treating hypoglycemia or ketonuria) performed by the parent on behalf of the young child with diabetes.

Keeping in mind the identified problem, the purpose of the study and the specific research questions to be addressed, a qualitative, interpretive approach was used to guide this research. This methodology will now be introduced.

Introduction to the Methodology

The phenomenological paradigm of qualitative research theory and methodology was used as the method of approach to this study. A qualitative, interpretative approach that focuses on the study of events as these are constructed in everyday social interactions was employed (Anderson, 1981). Qualitative research involves methods whereby characteristics, attributes and meanings of the phenomenon under study are identified, documented and interpreted (Leininger, 1985). These designs are typically selected when little is known about a phenomenon (Sandelowski, Davis & Harris, 1989). The literature review for this study presented in Chapter Two will reveal that the demands and stresses of the daily
management regimen on parents of children with diabetes has been recognized (Betschart, 1988). However, there is a paucity of research available regarding the perceptions of parents surrounding their lived experience of caring for a young child with diabetes. Because these perceptions of parents have not yet been identified, a qualitative research approach is appropriate for exploring this phenomenon. The specific method chosen is phenomenology.

Phenomenology is the study of human experience, and its purpose is to understand the structure and meaning of the lived experience (Knaack, 1984). The aim of phenomenological inquiry for the nurse is understanding (Sandelowski, 1986). Phenomenology is an inductive, descriptive research method that describes the lived experience from the subjective perspective of the person(s) who lived it (Omery, 1983). The task of the method is to investigate and to describe phenomena, including the human experience, in the ways these phenomena appear "in their fullest breadth and depth" (Omery, 1983, p. 50). The data gathered using this method are not limited to observable facts or objective empirical data. Instead, they include all available phenomena, together with the subjective meanings that these phenomena or experiences have for the participants in the study (Omery, 1983). Because the objective of this study is to "paint a picture" and increase the nurse's understanding of how parents perceive their lived experience of caring for their infant or toddler with diabetes, the phenomenological research method will guide the researcher's role, selection of participants, selection criteria, data collection procedures, sequencing of events in the study, measures to ensure reliability and validity (referred to as confirmability in qualitative research), data analysis and procedures for protecting human rights.

Specific details relating to the manner in which this method was interpreted and implemented will be described in Chapter Three.

For the purpose of this study, the following assumptions and limitations are acknowledged.
Assumptions

The following basic assumptions are directly pertinent to this investigation. It is assumed:

1) That parents of infants and toddlers with diabetes will have feelings and beliefs about caring for their child;

2) That parents are willing to share their experience and will provide an accurate and honest reporting of their perceived experience;

3) That issues surrounding diabetic management for their child will be of concern for these parents.

Limitations of the Study

The depth and richness of the data for this study could be limited due to the time constraints of the researcher. The number of participants may be determined by the fact that the population of young children with diabetes living in the Vancouver area is small. Also, because all parents who participated in this study were elicited through the Diabetes Program at B.C.’s Children’s Hospital in Vancouver, Canada, these parents may represent a specialized subgroup of the population.

Summary

This chapter has introduced the rationale for the study topic, the background to the problem, the conceptual framework chosen to guide the study, the purpose for the research, the specific questions used to direct the study and definitions of terms. The phenomenological paradigm of qualitative research theory and methodology has been briefly described and assumptions and limitations of the study acknowledged. Parents’ articulated concerns that lent credence to the need for this research were described, and the study was located within the context of nursing inquiry and within the domain of the popular arena of Kleinman’s (1978) health care systems explanatory models.
The following chapter will review selected literature related to care of children with diabetes, and is linked to the background and purpose of the study. Chapter Three will present a detailed description of the methodology used for this study. Chapter Four will present the findings of the study, and the participants’ accounts of their experience will be discussed. Chapter Five will discuss the findings of the study in relation to other authors’ published work on the topic. Chapter Six will provide a summary and conclusions of the study, and discuss the implications of the findings for nursing practice.
CHAPTER TWO

Review of Selected Literature

Introduction

The conceptual framework provides guidance for the literature review. Only a few studies are available on the chosen research topic, and no studies identified by the researcher specifically describe the lived experiences of parents who are caring for an infant or toddler under three years with insulin-dependent diabetes. However, several bodies of literature from areas that appear relevant and linked to the identified problem and purpose of the study will be reviewed. Both experiential and research-based articles will be examined in order to provide a broad overview and realistic understanding of the concepts underlying this study.

Because illness is a socially and culturally located phenomenon and forms part of the human experience (Kleinman, 1978a), literature pertaining to the impact of any chronic long-term illness on the child, the parent and the family will be examined first. This will be followed by a review of literature that has been specifically selected because of its relevance to care and management of diabetes in children of all ages. A third body of literature will be examined because the author’s work can be linked to the unique problems and needs of young children with diabetes and their parents.

The role of the literature review is to place this study in the context of work done by other authors, and provides a basis to guide the current research process. In Chapter Four of this report, the parents’ accounts of their experience of caring for an infant or toddler with diabetes will be presented, and in Chapter Five the findings of this study will be examined and discussed in relation to the findings of other researchers and authors.
The Impact of a Child's Long-Term Chronic Illness on the Child, the Parents and Family

Studies show that a child with a long-term chronic illness can have a devastating effect on family life. Changes in the health status of a child can alter family interaction patterns, roles, processes and functions (Banion, Miles & Carter, 1983). Freeman (1984) looks at how lifestyle modifications for the child and his or her family are necessary, and suggests that these changes may be easy to adapt to or may be extremely disruptive to family functioning. Freeman also suggests that the parents or primary caregivers are the most powerful subsystems in a family. Because these significant individuals create patterns into which the child fits, it is important for nurses to understand that modifications in lifestyle will depend primarily on the parents' perceptions of their child's illness, and their acceptance of it (Freeman, 1984).

In her interpretive study, Robinson (1983) found that families generally coped very well with the demands of a long-term illness in a child, which seemed to be a reflection of their attitude that coping is not a choice-making issue. However, Chan and Leff (1982) report that chronic illness not only interrupts the growth and maturation of the child, but also severely disrupts the growth and maturation of his/her parents. These authors suggest that diagnosis of a chronic long-term illness in a child causes stress for the entire family and can seriously affect family functioning. Whaley and Wong (1983) report that, because a family is a system of interdependent parts, a change in any one member of the system causes a corresponding change in every other member. For example, when illness occurs in a child, the child often becomes the principal directing force and, as such, causes major responses in each of the other family members. These responses are necessary in order that family members adapt and fit into a new and changed pattern (Freeman, 1984).

Several studies indicate that the mother is the person most involved with the coordination of care for the chronically-ill child (Banion et al., 1983; Chan & Leff, 1982; Freeman, 1984). These authors suggest that, because the mother is so intimately bound to the details of the child's illness and needs, any
problems that she has in coping with the daily management regimen may affect the entire family and alter parental roles and communication patterns within the family (Banion et al., 1983). How the parents perceive their child’s illness is also a significant factor in how the child and family adapts (Chan & Leff, 1984). Robinson’s study (1983) suggests that illness will be interpreted differently by each member of the family and will be subjectively experienced in different ways by different individuals. These perceptions will be based on past experiences, family beliefs, values, and cultural orientation, and can change during progression of the child’s illness and the family’s adaptation. Other studies confirm Robinson’s findings by reporting that a parent’s or primary caregiver’s ability to adapt to the new responsibilities for their child’s care depends on that individual’s values, beliefs, past life experiences with coping with chronic illness, and ways of feeling about the situation (Anderson et al., 1989; Hayes & Knox, 1984).

Other studies show that the extent to which a child’s illness affects the family also depends on the extent and nature of the illness and the required management regimen (Bouma & Schweitzer, 1990). For example, in their study involving 84 mothers of children with diabetes, Banion, Miles and Carter (1983) reported that major factors affecting the familial impact of chronic disease in a child are the amount of time spent in the home managing of the disease, and the amount of change in lifestyle that must be made. These authors reported that in a chronic illness such as diabetes, the daily care and monitoring of control at home necessitates large expenditures of time and effort by the parents. The lifestyle and interpersonal relationships of the entire family are affected, as members must rearrange and establish their lifestyle to accommodate the requirements imposed by the diabetic regimen and the treatment demands. Betschart (1988) and Tze (1989b) reported that the demands and stresses of managing the diabetic regimen for a child can contribute to severe stress and neurotic behaviour in parents that may require professional intervention to overcome. Parents of children with diabetes are expected to perform painful and intrusive procedures such as daily insulin injections and blood glucose monitoring. These procedures are essential
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to the child’s long-term well-being and survival, but can evoke fear, anxiety, and feelings of helplessness and overwhelming guilt and resentfulness in those expected to undertake and perform such procedures (Hatton, 1988; Tze, 1989b).

Several theorists report that the majority of difficulties experienced by parents centre on extensive treatment regimens, and that these regimens may be so demanding that they pose greater problems for the family than do the symptoms of the child’s long-term illness (Bouma & Schweitzer, 1990; Chan & Leff, 1982; McCollum, 1981). Because diabetes has been recognized as a chronic, lifelong illness requiring a complicated daily management regimen (Betschart, 1988; Brink, 1987; Hatton, 1988; Hunt & Alojado, 1989; Krall & Beaser, 1989; and Tze, 1989b), it is important that researchers and health care professionals better understand the lived experiences of parents and children who are coping with the impact of this illness on a day-to-day basis.

The Impact of Diabetes in Children on the Parents and Family

Several studies are available that discuss compliance or lack of compliance with the diabetic management regimen (Daneman, Siminerio, Transue, Betschart, Drash & Becker, 1985; Friedman, 1987; Hilton, 1986). However, few studies address the frustrations, stresses and demands on inner resources surrounding invasive procedures performed by the parents of children with diabetes, and few empirical investigations on coping behaviours of families struggling with these demands on a daily basis have been conducted (Betschart, 1988).

MacMillan, Muraca and Murk (1988), in their study to evaluate a program implemented to teach nurses successful blood glucose monitoring techniques, concluded that this added component to an already complex and demanding diabetic management regimen stretched not only the resources of nurses, but would require inner strength and resourcefulness on the part of parents and children to perform this task on a daily basis at home. A study conducted by Templeton, Burkhart, Anderson and Bacon (1988)
concluded that invasive procedures such as blood glucose monitoring provided parents and children with indications of "good" or "poor" diabetic control, helped to confirm hypoglycemia and hyperglycemia and allowed more flexibility in the dietary regimen and insulin administration. However, the perceptions of children and parents surrounding their experience and concerns with these procedures were not elicited.

With regard to complexities of the diabetic management regimen, Kovacs and Feinberg (1982) dramatized this problem when they reported that no families in their sample initially were able to cope effectively without neurotic behaviour.

Betschart’s study (1988) was instrumental in directing this researcher towards the current study. Her descriptive survey involved 145 parents of children between the ages of 5 and 17 years with diabetes. Parents in the study each attended an educational seminar designed to review diabetes management for their child. During the seminar, parents wrote anonymous responses to specific questions dealing with a) their understanding of glycemic control, b) their feelings of guilt associated with various aspects of diabetes management, and c) their individual ways of coping with the struggles and frustrations of daily life. Analysis of the responses resulted in indications that parents and their children with diabetes face numerous difficult tasks every day, and that the process of accepting the diagnosis of diabetes in a child is similar to that of mourning (Betschart, 1988, p. 400). Betschart concluded that parents’ understanding of, and guilt over their children’s diabetic control frequently led to stresses and needs not currently being addressed or met by health care professionals. These stresses can contribute to parental behaviours of child abuse, psychological neglect, and inability to provide love and security for the child. Betschart also identified areas of stress and feelings of guilt for parents surrounding issues of inflicting pain and suffering on their child, and the inability to control the child’s blood glucose levels. Her results were reinforced by other studies which indicated that the stresses and demands of the diabetic management regimen on parents have long been recognized (Allen, Affleck, Tennen, McGrade & Ratzan, 1984; Etzwiler & Sines, 1962; Kovacs & Feinberg, 1982; Schafer, Glasgow, McCaul & Dreher, 1983).
In a study conducted to determine the association between knowledge and the level of self-management in children with diabetes, Christensen (1983) surveyed 157 children attending a diabetic summer camp. The extent of knowledge about diabetes was determined by the children's responses to a knowledge questionnaire. Scores were analyzed using a t-test and regression analysis. Results showed a significant association between the child's knowledge base and level of self-management, and indicated that children with diabetes are more likely to achieve effective self-management when adequate knowledge of their illness is acquired. Appropriate knowledge and skills should be demonstrated by both the parents and child if the diabetes is to be effectively controlled (Christensen, 1983, p. 552).

Henderson and Thompson (1992) explored the use of life-size body drawings and puppet play to increase age-appropriate knowledge and enhance emotional adaptation in preschool and early school-age children with diabetes. These nurse educators described a program designed to encourage, validate and normalize the young child's verbal expression of feelings. Invasive and painful procedures and loss and grief were common emotional issues explored and shared by parents, siblings and the young child with diabetes. Because nurses and other health care professionals are responsible for teaching the necessary knowledge and skills to both the child with diabetes and his or her parents, collaboration and understanding between family members and health care professionals should be fostered.

When discussing the family and childhood diabetes, Lorenze (1991) stated that "few childhood diseases rival insulin-dependent diabetes mellitus in terms of the high degree of family involvement needed for day-to-day management" (p. 262). LaGreca (1991) reiterated that insulin dependent diabetes mellitus is a challenging and complex disease to manage effectively, and that the demands of insulin injections, blood glucose monitoring and dietary and activity programs have lifestyle implications that make this a disease requiring a high degree of family involvement (p. 269). This research found that during early childhood, parents typically assumed primary responsibility for the child's diabetic care. However, findings also indicated that even throughout later childhood and adolescence, family members
remain involved in many aspects of the diabetes care. In fact, despite conventional wisdom that children should assume responsibility for their own diabetes care as early as possible, accumulating evidence strongly suggests that family involvement is both desirable and beneficial for youngsters with this chronic illness regardless of age (LaGreca, 1991, p. 269). LaGreca (1991) also reported that problems occur if children are left with a high degree of responsibility for their own care, and youngsters left entirely responsible for their own insulin administration and monitoring have been found to be in poorer metabolic control than those whose parents are consistently involved with assisting and supervising the diabetes regimen for their youngster (p. 269). In their study to assess family sharing of diabetes responsibility, Anderson, Auslander, Jung, Miller and Santiago (1991) found that children assume increasing responsibility with increasing age. However, health care professionals should not assume that parents and children communicate about the sharing of diabetes responsibilities in the family, or about changes in management as they occur (p. 263). In their study, these researchers used factor analysis on childrens’ and parents’ responses to a Diabetes Family Responsibility Questionnaire, in an attempt to determine the relationship between patterns of mother-child sharing responsibility for diabetes related tasks, and the adherence and metabolic control of the diabetic child. Results of this study supported those of LaGreca (1991), in that correlations were found between metabolic control for the child and the amount of involvement the parents retained in the diabetes management regimen. Because this study indicated that in mother-child dyads, lack of communication about who "takes responsibility" can significantly affect diabetic control for a child, these researchers recommended that health care practitioners should consistently help families to identify diabetes tasks for which no one in the family takes responsibility (p. 263).

With very young children, shared responsibilities and open communication between both parents was also a factor in the achievement of good metabolic control for the child (Anderson et al., 1991). The study by Anderson and colleagues (1991) also examined socioeconomic status, educational and
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occupational levels of the parents, marital status of the parents and age of the diabetic child. Multiple regression analysis indicated that these were all factors significantly influencing the overall amount of family involvement in the child’s diabetic management. These researchers recommended that studies undertaken to examine individual family members’ perceptions of who takes responsibility for the complex tasks of diabetes management would provide valuable information for health care professionals working with the family system around adherence and support issues (p. 265). Their findings emphasized the importance of ongoing family communication regarding expectations and responsibility for diabetes management tasks with children of all ages. Although the mother-child dyad was emphasized, the Anderson and colleagues’ study results also indicated that lack of communication and differences in expectations regarding the sharing of diabetes responsibilities also existed between the parents of diabetic children. Because of the long-term nature of the disease, this study indicated that in many families, the focus on diabetes management may decrease after the family stabilizes following a crisis period, such as diagnosis of an acute diabetes-related episode (Anderson et al., 1991, p. 267).

In their longitudinal study that followed mothers of newly-diagnosed insulin-dependent diabetic children over a six-year period, Kovacs, Iyengar, Goldston, Orbrosky, Stewart and Marsh (1991) assessed the psychological functioning and levels of maternal depression experienced over time. Self-report symptom inventories were used and analyzed. Initial findings indicated that mothers initially reacted to the diagnosis of diabetes in their child with mild depression and overall distress, but that these initial reactions subsided in about 6 to 9 months. Later findings indicated that after this initial phase of adjustment, there were slight increments in maternal depressive symptoms over the duration of the child’s illness. Psychological distress, including symptoms of anxiety, somatization, anger, suspiciousness and dysphoria also increased with the duration of the child’s diabetes. These researchers also found that the degree of emotional upheaval mothers experienced at the time diabetes diagnosed in their child was a strong predictor of their later symptomatology (Kovacs et al., 1991, p. 276). The Kovacs et al. study is
still in progress, but revealed findings that appear to indicate that the maternal depression and distress was not associated with the child's compliance or diabetic control. However, mothers who reported greater general distress also reported coping more poorly with their child's diabetes. In Jacobson's (1991) commentary on the Kovacs and colleagues' study, it was suggested that the initial increase in distress and depression was consistent with a period of mourning that is likely to occur with the onset of a chronic, life-threatening illness such as diabetes; and that the slight increases in symptoms over the long term are consistent with other research findings about the effect of the course of diabetes in children and its influence on mothers' lives. The fact that the initial degree of upheaval experienced by mothers at the time their child was diagnosed could be a predictor of their later symptomatology was seen by these researchers as an important point for health care professionals to consider. Early psychological interventions to identify sources of stress, reduce stress and improve coping could be beneficial to these mothers, their children and family functioning (Jacobson, 1971, p. 279). This study supports the work of other researchers such as Koski, Ahlas, and Kumento (1991) who report that past experiences, past history of depression, and family dynamics can play a major role in how mothers react to the diagnosis of diabetes in their child. In their longitudinal study of family functioning and its relationship to coping with diabetes in children, Koski and colleagues identified several family functioning styles such as conflictual, chaotic, or supportive of freedom for individual growth, that can significantly impact on the ability of family members to effectively manage a child with diabetes (Koski et al., 1991, p. 289).

These authors indicate that in the past, more emphasis has been placed on quantitative methods of research using multivariate statistical models that attempt to mirror the complexity of family interactions and a child's diabetes. They recommend that more qualitative studies should be undertaken in light of the fact that areas of family life that are critical in the management of diabetes in a child have not yet been fully identified (Koski et al., 1991, p. 289).
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The majority of studies previously reviewed on children with diabetes and their families have involved adolescents or school-age children, and only a few studies include data pertinent to the unique management problems of young children under three years. Because the stresses and needs surrounding care of these toddlers and infants are quite different from those of older children, it is important for nurses and other health care practitioners involved in their care to recognize the characteristics and special needs of both these children and their parents (Tze, 1989a).

**Diabetes in Infants and Toddlers under Three Years: Unique Problems and Needs**

Young children under three years of age who have diabetes are totally dependent on others for management of their disease. Consequently, how the parent adjusts to and copes with the day-to-day care of the young diabetic child can be a key factor in reducing the impact of the child’s diabetes on family life, and in enhancing the adjustment of the child (Banion et al., 1983).

Wysocki, Huxtable, Linscheid and Wayne (1989) evaluated the adjustment to diabetes mellitus in preschoolers and their mothers. Mothers completed the child behaviour checklist, Parenting Stress Index, Parents’ Diabetes Opinion Survey and the Preschool Diabetes Behaviour Checklist constructed specifically for the study. Maternal attitudes were correlated with the children’s disease-specific behaviour problems. However, findings of the study revealed that psychological adjustment of the child was not predictive of diabetes-specific behaviour problems.

In the previously cited study by Banion, Miles and Carter (1983), it was also found that the younger the child, the greater the maternal concerns about hypoglycemic reactions and availability of support systems. These investigators reported that few studies are available that analyze the difficulties parents have in managing a child with diabetes. They developed a Diabetic Management Concern Questionnaire based on eleven aspects of diabetic care that could be of concern to mothers. These aspects
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included injections, diet, control, testing, hypoglycemic episodes, finances, the amount of support and help available, time demands, feelings that the illness is a stigma, and fears for the future. Mothers with children ranging in age from 1 to 17 years completed the questionnaire rating each of the eleven aspects of care on a Likert-type scale. Results were analyzed using Duncan's New Multiple Range Test, and analysis of variance for repeated measures. This study involved mothers of children with diabetes of all ages, and did not specifically address the perceptions or experiences of mothers with children under three years. However, a secondary purpose of the study was to explore how age and sex of the child, age at diagnosis, illness duration, marital status, and socioeconomic status of the mother were related to the mother's perception of the problematic aspects of care. Results indicated that the three dimensions of diabetes management perceived as most problematic to all mothers were hypoglycemic episodes, diabetic control and concerns for the future. Mothers of lower socioeconomic status were more concerned about finances, availability of support, and the social stigma of diabetes. In age-related comparisons, the study results indicated that hypoglycemic episodes and availability of help and support were two aspects of care significantly correlated with age. For example, the younger the child, the greater the maternal concern about these two aspects of care. Results also indicated that the younger the child at time of diagnosis, and the shorter the duration of illness, the greater the mother's concern with injections and maintaining diabetic control. The sex of the child had no effect on dimension scores (Banion et al., 1983).

This study provided some information on maternal concerns related to managing a child with diabetes. However, the investigators acknowledged that further studies are required in order for health care professionals to better understand the perceptions of mothers concerning caring for their diabetic children. They suggested that understanding the parents' experience could direct health care professionals towards providing better services to meet the physical care needs of the child, as well as the psychosocial needs of the entire family. Findings from this study further indicated that understanding the parents'
perceptions of day-to-day care of their child is of particular importance when diabetes is diagnosed at an early age, because young children are so dependent on others for their very existence (Banion et al., 1983).

A literature search revealed no studies describing the experience of parents who care for infants or toddlers with diabetes on a day-to-day basis. However, in an article describing a developmental approach to diabetes in children, birth through preschool, Lipman and colleagues (1989) report that, for an infant who is just learning to trust those who provide comfort and love, diabetes can pose a stumbling block. Suddenly, the most trusted person in the infant’s environment — the parent — must inflict pain on him/her repeatedly. An infant’s tiny fingertips provide little surface area for repeated capillary blood tests, and the parents experience extreme anxiety at the thought of causing their infant pain. With preschoolers, Lipman and colleagues found that inflicting pain through insulin injections and blood glucose monitoring can affect parent/child relationships. Although their article was not research-based, it directed this researcher towards the need for research in this area.

Although not specifically linked to parents of infants or toddlers, findings from a study by Marteau and colleagues (1987) showed significant differences between the goals of medical personnel and the goals of parents in treating children with diabetes. In the introduction to their study these investigators acknowledged that most studies conducted to analyze treatment success for the child with diabetes are concerned largely with the extent to which the goals set by the doctor have been achieved. Disparity between goals set and goals achieved have been generally understood by health care professionals as a problem of patient compliance (Marteau et al., 1987). In these studies there has been an implicit assumption that doctors and parents are aiming to achieve the same goals for the child, and the fact that doctors and parents may not share the same goals has not been considered.

In the Marteau and colleagues’ study (1987), the four related aims were 1) to compare the goals of treatment of doctors caring for a child with diabetes with the goals of parents, 2) to assess the extent to which the parent’s goals of treatment predict the level of blood glucose control achieved by the child,
3) to examine whether the concepts of control used by doctors coincide with the concepts of control used by parents, and 4) to examine the attitudes and beliefs that influence the formation of each respective goal. The investigators postulated that a disparity of goals between parents and doctors would arise from a disparity in beliefs and attitudes towards the child's diabetes. The beliefs and attitudes of subjects were examined according to those outlined by Becker, Maiman, Kirscht, Haefner, Drachman and Taylor (1979) in the Health Belief Model.

Subjects in the study were 65 sets of parents of children with diabetes aged between 5 and 16 years. They completed scales on their goals of treatment and their beliefs and attitudes towards diabetes. The parent’s scales were compared with those completed by 104 pediatricians, and 119 physicians with a particular interest in diabetes. The scales were designed to measure perceived seriousness of diabetes, perceived vulnerability of the child to short-term and long-term complications, perceived benefits of treatment and perceived barriers to treatment. Parents of the children with diabetes completed the scales individually at home. Pediatricians and physicians completed the scales making ratings for a hypothetical child with insulin dependent diabetes. Results indicated that parents preferred children to show higher glycemic levels than doctors. This preference was associated with the belief that hypoglycemic episodes were serious for their child and should be avoided. Parent’s goals were more related to hypoglycemia than hyperglycemia and were related to their experiences of dealing with such episodes. While the risk to life in childhood due to a hypoglycemic coma is considered low by doctors, for parents the event is frightening and frequently accompanied by fear of their child dying.

In comparison, the doctors’ goals were found to be related more to beliefs about hyperglycemia. Doctors perceived hyperglycemic coma as far more serious and more difficult to treat than hypoglycemia. Their knowledge and past experience led them to a belief that diabetic ketoacidosis is a major threat to life for the child. Their goal of achieving normoglycemia for the child with diabetes was based on the potential benefits of reducing or avoiding long-term complications. Parent’s perceptions of diabetic
complications were lower than those of doctors and could reflect the fact that parents’ have less experience of people with diabetes, over the long-term (Marteau et al., 1987).

These results indicate that doctors and parents do not always share the same goals in treating children with diabetes, and the researchers suggest that treatment failure for the child, and communication problems between health care professionals and parents, could result from these differences in perceptions and goals. They conclude that a more effective clinical alliance would result if the goals, beliefs and attitudes of parents were better understood by health care professionals. These findings are congruent with the belief inherent in Kleinman’s conceptual framework that guides this study. They also support findings of Banion and colleagues (1983) who reported that hypoglycemic episodes were perceived by mothers of children with diabetes as one of the most problematic aspects of diabetes management, and that the younger the child the greater the maternal concern expressed.

In a recently published research article, Puczynski, Puczynski and Ryan (1992) provided new information about the acute and long-term effects of hypoglycemia in diabetic children on such cognitive functioning as learning, memory, reading and visuospatial skills. These researchers closely monitored 24 diabetic children at a summer camp and administered a battery of neuropsychological tasks to non-symptomatic children and to children recovering from mild hypoglycemic episodes. Comparison of group scores demonstrated statistically significant lower scores in 5 out of 12 tasks in the group recently recovered from mild hypoglycemic episodes. The study results also indicate a deterioration in mental efficiency following periods of hypoglycemia in children. The time required for cognitive recovery following such episodes was not determined by this study. These same researchers also reported on a number of studies that suggest children who are diagnosed with insulin dependent diabetes at a young age are at increased risk for the development of mild to moderate cognitive impairment (Ryan, Vega & Drash, 1985; Rovet, Ehrlich & Hoppe, 1988).
Ryan and colleagues (1985) administered a series of neuropsychological tests to adolescents with a history of insulin dependent diabetes and compared results with a group of healthy controls. Results demonstrated that children who acquired diabetes prior to the age of four years performed more poorly than did those with later onset diabetes or healthy controls in tasks of visuospatial ability, and measures of memory and intelligence. It was hypothesized by these researchers that the developing nervous system of the young child is particularly vulnerable to recurrent and/or undetected episodes of hypoglycemia. Because all children with insulin dependent diabetes are susceptible to episodes of mild or moderate hypoglycemia, it was suggested that "management of diabetes in young children is complicated by the parents' efforts to distinguish symptoms of hypoglycemia from normal behaviour seen in these children during their infant, toddler and preschool years" (Puczynski et al., 1992, p. 152). Consequently, it was recommended that more frequent blood glucose measurements are necessary to prevent repeated and undetected episodes of hypoglycemia in young children.

Puczynski and colleagues (1992) acknowledged that the management of insulin dependent diabetes in children is a challenging and often frightening task for children, their parents and school personnel (p. 151). They also implied that it is critical for health care professionals to communicate the effects of early onset disease, and the transient or long-term effects of acute hypoglycemia on a child's cognitive functioning to the parents. While acknowledging that medical emphasis is focused primarily on maintaining optimal blood glucose levels to prevent the development of long-term complications associated with hyperglycemia in diabetes, Puczynski et al. (1992) also suggest that avoidance of acute hypoglycemic episodes is also critical in the overall management of young diabetic children. This dichotomy of expectations in diabetic management could pose a threat to the parents' ability to cope with an already complex situation, and emphasizes the need for nursing interventions based on an understanding of the impact of the management regimen on the day-to-day lived experience as articulated by the parents.
Summary

The literature review has indicated that parents and primary caregivers experience their child’s diabetes according to their own values, beliefs, cultural and socioeconomic backgrounds. Few studies are available to indicate the impact of the complicated daily management regimen on parental adaptation, parental roles and family functioning, and no studies are available to provide nurses with an understanding of the parents’ perceptions concerning their daily experiences of caring for a young diabetic child. Because parents are the most powerful subsystems in the family system and create patterns into which the children fit, it is important for the nurse to view the parents and the child in the context of the family. Since an infant or toddler under three years with diabetes is dependent on the parents for his/her very existence, the perceptions of these significant individuals must be understood.

From the literature it appears that the diagnosis of diabetes in an infant or toddler results in multiple stressors for the parents. These stressors are related to the difficulties parents have in managing a child with diabetes. Aspects of concern to parents included insulin injections, blood sugar testing, the child’s diet, controlling blood sugar levels, dealing with hypoglycemic episodes, the amount of support available and the extent to which parents were required to make changes in lifestyle. Results of studies also suggested that the younger the child was at the time of diagnosis, and the shorter the duration of diabetes in the child, the greater the concern over injections, hypoglycemia and maintaining blood sugar control.

The literature also indicates that parents respond to their child’s diabetes with distress and depression consistent with a period of mourning. It also suggests that the initial degree of upheaval experienced by the parents at the time the child is diagnosed could be a predictor of future distress and ability to cope.

Diabetes, by virtue of its chronic nature and complex management regimen, requires parents to cope with ongoing, day-to-day stressors and concerns, and to make numerous adjustments in their lives.
Parents of infants and toddlers are concurrently coping with the stressors of early development issues for their child, and the building of parent/child relationships. Inflicting pain on their young child through insulin injections or blood testing was seen as a factor affecting parent/child relationships.

Although the literature indicated that the management of insulin dependent diabetes in children of any age is a challenging and often frightening task, little has been written about the experience of families having an infant or toddler with diabetes. Studies did indicate that, in very young children, shared responsibility and open communication between both parents could be a factor in the achievement of good diabetic control for the child. However, no studies reviewed were directed toward the initial impact of the acuity of the illness at the time of diagnosis for the young child, or the effect this impact had on parental relationships or interactions.

The literature did suggest that significant differences between the goals of medical personnel and the goals of parents in treating children with diabetes did exist. It also indicated that, in order for health care professionals to provide appropriate support and quality care for these families, a better understanding of the parents' perceptions of their child's condition is crucial. This study was designed to add to that understanding.
CHAPTER THREE

Methodology

Introduction

As indicated in Chapter One, the phenomenological paradigm of qualitative research theory and methodology was used as the method of approach to guide this study. Phenomenology is a qualitative, interpretive method that provides a particular way of focusing, thinking and acting. It concentrates on the subject’s experience rather than concentrating solely on subjects or objects (Munhall & Oiler, 1986, p. 57). Phenomenology directs the researcher to study the human experience. In applying this approach, the researcher seeks to see things from the subject’s point of view, and thus to understand the meaning attached to the experience by the subject (Giorgi, 1975; Munhall & Oiler, 1986). This chapter describes the manner in which the method was interpreted and implemented in the selection of participants, ethical considerations, data collection and data analysis.

Selection of Participants

Using phenomenology, participants in the study were selected on the basis of their experience with the phenomenon being studied and were considered "experts" in the area under investigation. A purposive sample was used for this study (Sandelowski et al., 1989). In purposive sampling, subjects are selected according to certain characteristics and knowledge each possesses; this ensures representativeness of the information required. The focal group sampled for this study was made up of parents who have young children under three years with insulin dependent diabetes. The phenomenon being studied was the lived experience of caring for such an infant or toddler as perceived by the parents. Consequently, sample selection was according to the subject’s ability and desire to provide information that contributed to understanding and insight in relation to the phenomenon being studied (Morse, 1986). Purposive sampling
rather than statistical subject selection is used in this method to ensure maximum variation of information obtained (Sandelowski et al., 1989). Theoretically, the sample size should be determined by the quality, amount and completeness of the information offered by the subjects. Data collection and analysis occur simultaneously, and the need to further explore, confirm or refute the emerging themes or concepts determines the selection of the sample. Sampling and data collection cease when no new concepts are emerging from the data and theoretical saturation has occurred (Woods & Catanzaro, 1988). This occurs when the themes or elements appear complete, do not have gaps, make sense and have been confirmed (Morse, 1986). However, because of the length of the data-gathering interviews, and the detail of the complete description of data required in this type of study, sample size is usually small (Omery, 1983).

For this study, a sample of eight families was selected; eight mothers and five fathers from these families participated in the interviews. The sample was obtained through the Diabetic Program at B.C.’s Children’s Hospital.

Criteria for Selection

The criteria for selecting parents who participated in this study included the following:

1) The subjects were the parent(s) of an infant or toddler with diabetes.
2) Each subject interviewed would form part of a two parent family.
3) Both parents would be interviewed together, when possible, otherwise the mother of the young child with diabetes would be interviewed.
4) The young child was under the age of three years at the time his/her diabetes was diagnosed, and was still under three and one half at the time his/her parent(s) were interviewed.
5) A minimum of two months had elapsed since the time of diagnosis for the child.
6) During the past two months or longer, the parent(s) had assumed full responsibility for the day-to-day care and management of the child's diabetic regimen.
7) The subjects could communicate in English, were willing to be interviewed, and lived within the greater Vancouver area.

When considering the above criteria it should be noted that the seventh criterion was not met by one family selected for the study. This family moved out of the greater Vancouver area shortly before the study commenced. However, because the infant with diabetes in this family had been diagnosed at a very early age (5 weeks), the researcher elected to travel the distance to the family’s new home in order to obtain the richness of data provided by those parents’ articulated experiences.

It should be noted that only two-parent families were considered eligible for this particular study. Although it is recognized that many single parents care for children who have diabetes, the researcher was also cognizant of the fact that the lived experience of single parents could be very different from the lived experience of two parent families. Consequently, such differences might contribute to excessive variability in data. However, the researcher does recognize and advocate a need for further studies to explore the experience of single parents who are caring for an infant or toddler under three years with diabetes.

Selection Procedure

Families were selected from a computer generated list of children under three years of age who are followed by the Diabetes Program of British Columbia’s Children’s Hospital in Vancouver, Canada. The Program Director was aware and supportive of the proposed study and gave his permission for families meeting the criteria to be approached and enrolled. Eligible parents were initially contacted by a member of the Diabetes Management Team, either during a clinic visit or by telephone. The purpose and objectives of the study were explained to them and a participant information letter (see Appendix A) containing detailed information about the study was subsequently mailed to each interested parent. Families wishing to participate in the study or requesting further information were asked to contact the Diabetic Clinic and leave their name and telephone number.
Because of her familiarity with the Diabetes Management Program, and with some of the families meeting the criteria for inclusion in this study, the researcher did not contact any potential subjects until they had made an independent choice to call the Diabetic Clinic for more information or to indicate their desire to participate in the study. This avoided any possibility of coercion on the part of the researcher. Once parents had responded and left their name and telephone number, they were contacted by the researcher. The study was then explained in more detail, questions were answered, and explanations of procedures for protecting human rights and maintaining confidentiality were provided. Appointment times for the first interviews were arranged with families who were eligible and willing to participate. Out of twelve families originally contacted by the Diabetes Management Team, two of the young children with diabetes no longer met the criterion of age. Although these children were under three years of age when diagnosed with diabetes, they were over three and one-half years when the parents were contacted by the researcher. Because these parents had indicated an interest in participating in the study, they were thanked sincerely for their interest, and advised by the researcher that they would be contacted again only in the event that insufficient families meeting the required criteria were found. Because of their enthusiasm and support, they were assured that should a similar study be conducted in the future, with criteria suitable to include their child, they would definitely be invited to participate. It was also gratifying for the researcher to receive several enquiries from the parents of other children with diabetes who had heard about the study and were interested in becoming participants. These parents were also thanked most sincerely for their interest and assured that they would be contacted in the future should further studies of this nature be considered.

Of the remaining ten families who had initially been contacted by the Diabetes Management Team the researcher was unable to successfully contact one family despite several attempts, which included leaving messages with babysitters. Although this family had originally indicated a willingness to participate in the study, the researcher felt it was inappropriate to persist with attempts to contact them
once messages had been left to which the parents did not respond. Each of the other nine families selected by the Diabetes Management Team agreed to participate in the study. Initial interviews were arranged with seven of the families within a relatively short span of four to five weeks, and interviews with the two remaining families were arranged for later dates because of the Christmas vacation season which occurred during the interim. Prior to the first interview a written consent to participate in the study was obtained from the parent(s) (see Appendix A). A copy of the signed form, which also explained the purpose and objectives of the study was left with the participating parent(s).

Due to an unexpected snowfall it was necessary for the researcher to cancel the initial interview with one of the families. During the telephone call to cancel and reschedule this appointment the researcher and the mother of the young child with diabetes spoke at length. The mother shared many of her experiences of caring for her child during this telephone conversation, and addressed several of the initial research questions. Field notes were recorded by the researcher. Unfortunately the rescheduled interview with this family was also cancelled at the last minute due to a serious accident incurred by an older sibling in the family. During the ensuing telephone conversation the mother again shared many of her daily experiences of caring for her young diabetic child, as well as describing the added stress of caring for a teenage accident victim. Because of the family circumstances the researcher and mother agreed that it was not appropriate to reschedule another interview at that time. However, the mother suggested that any of her described experiences articulated during the telephone conversations could be used as data for the study if deemed appropriate. Although the researcher kept field notes, this family was not included in the demographics for the study and the mother’s experience was not used as part of the data collection or analysis. However, some of the mother’s significant statements, captured and recorded in the field notes, were used for reference and interest by the researcher when confirming and clarifying emerging themes and concepts from the participating parents’ described experiences.
Characteristics of the Participants

A total of eight families participated in the study. Each was a two-parent family and each had a young child who had been diagnosed with insulin dependent diabetes before the age of three years. All the families were Caucasian although they came from a variety of cultural and ethnic backgrounds. The parents could communicate in English and were willing to be interviewed and to share their experiences. Most of the parents were Canadian born, although one father emigrated from Scotland at the age of 20 years, two parents were of Italian background, two of Jewish heritage, one of Eastern European descent, one of Scandinavian origin, and several came from families with roots in Great Britain, the United States and Australia. The socioeconomic status, educational backgrounds, style of living and geographical location varied among families. Three families lived in Vancouver, three in the greater Vancouver area and two in rural communities. Six families lived in private single family homes, two lived in town-house or apartment complexes. The occupations of the parents also varied. Table I provides a synopsis of the demographic data for the families participating in the study. However, the following discussion provides more detailed information on the young children with diabetes, their siblings and their family history of diabetes.

Young Children with Diabetes

The infants and toddlers involved in this study ranged in age from 5 weeks to 2 years, 5 months at diagnosis, with an average age of 17 1/2 months at the time of onset of diabetes. The length of time since diagnosis ranged from 5 months to 2 years, 2 months, with an average time since diagnosis of 13 1/2 months. All the children except one were still under 3 years of age when their parents entered the study and were interviewed for the first time. One child was just 3 years. Two additional children reached their third birthday during the course of the study.
<table>
<thead>
<tr>
<th>MOTHERS' OCCUPATIONS</th>
<th>FATHERS' OCCUPATIONS</th>
<th>INFANT OR TODDLER WITH DIABETES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three mothers were teachers. One mother returned to teaching six months after the child's diagnosis. Two became full-time homemakers following the child's diagnosis.</td>
<td>Accountant</td>
<td>15 months</td>
</tr>
<tr>
<td>One mother worked in advertising, but became a full-time homemaker following the toddler's diagnosis.</td>
<td>Librarian: World Health Organization</td>
<td>19 months</td>
</tr>
<tr>
<td>One mother was a doctor's receptionist.</td>
<td>Printer: daily newspaper; night shift</td>
<td>5 weeks</td>
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<tr>
<td>One mother was a registered nurse. Both returned to part-time work several months after their child was diagnosed.</td>
<td>Dentist</td>
<td>22 months</td>
</tr>
<tr>
<td>One mother was a librarian and returned to full-time work following the toddler's diagnosis.</td>
<td>Shipping and handling; night shift</td>
<td>6 months</td>
</tr>
<tr>
<td>One mother was a full-time homemaker.</td>
<td>Bus driver</td>
<td>25 months</td>
</tr>
<tr>
<td></td>
<td>Boat builder and designer</td>
<td>23 months</td>
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<td></td>
<td>Writer and editor in advertising</td>
<td>29 months</td>
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<table>
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<tr>
<th>Age at diagnosis</th>
<th>Time since diagnosis</th>
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<tr>
<td>15 months</td>
<td>17 months</td>
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<td>19 months</td>
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<td>23 months</td>
<td>11 months</td>
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<td>29 months</td>
<td>6 months</td>
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</table>
Siblings

In five of the families participating in the study the young child with diabetes was the only child in the family. However, this changed in one family in which the mother delivered a baby girl several weeks after the study commenced. In another family the mother became pregnant with her second child during the course of the study. In the other three families two of the infants or toddlers with diabetes had younger siblings. One sibling was born just two weeks before the researcher's first interview with the parents. Another sibling was a year old and was born prior to the onset of diabetes in her two year old brother. In one family the young child with diabetes had a five year old sister. No family in the study had more than two children.

Family History of Diabetes

Of the eight sets of parents participating in this study only one family had no known history of diabetes. One family reported a distant maternal great aunt who developed Type II diabetes in old age. However, little significant connection is made between this type of non insulin dependent diabetes and early onset Type I (insulin dependent) diabetes in children (Tze, 1989a). The mother in this family reported the experience of giving insulin injections to a diabetic pet owned by her parents. In another family the mother developed gestational diabetes during her pregnancy with the toddler who later developed diabetes. A distant, elderly, paternal cousin was also reported to have Type II (non insulin dependent) diabetes by this family. In the fourth family a maternal great grandfather was diagnosed with insulin dependent diabetes, and the mother participating in the study experienced episodes of hypoglycemia. In the fifth family the maternal grandfather developed Type II diabetes initially but became insulin dependent at the age of 50 years. The remaining three families each reported a history of Type I diabetes with early onset in close extended family members. For example, in one family a paternal uncle (father's brother) was diagnosed at 13 years of age. In another family a paternal first cousin (father's
brother’s child) developed Type I diabetes at 12 years of age. In the final family two maternal first cousins (mother’s brother’s children) were diagnosed at 2 years and 12 years respectively. The maternal grandmother in this family also had Type I diabetes.

This section has described the selection of participants for the study, and provided some demographic data on the families selected. These demographics are useful in that they provide insight into the environments from which the parents perceived their experience. Past experience with diabetes in a close family member, particularly Type I diabetes, appeared to have some impact on the parents perceptions of diabetes in their own infant or toddler, and this will be described later during discussion of the analyzed data.

**Procedures for Protecting Human Rights**

Prior approval for this study was obtained from the University of British Columbia’s Screening Committee, and British Columbia’s Children’s Hospital’s in-Hospital Research Review Committee. Rights of the participants were protected by: a) providing a full description and explanation of the study and the researcher’s expectations to all participants prior to obtaining their written consent; b) assuring parents that non-participation in the study or withdrawal from the study would in no way jeopardize their child’s care, or the parents’ relationship with the Diabetes management team; c) reminding parents of their right not to participate or their right to terminate an interview or erase a tape at any time; d) informing participants of anonymity and confidentiality of data, and that taped data would only be shared with members of the thesis committee, and would be erased immediately following completion of the study; e) informing participants that no names or identification would appear in any written reports; f) assuring parents that the study involved no expected risks for themselves or their child; g) obtaining written consents to participate from all subjects; h) and explaining the potential benefits and outcomes of the study — such as nurses better understanding the parents’ perspective. In the event that unmet needs were identified
Researchers' Role

Because of the in-depth method of data collection used for this study, the researcher's role was also explained to participants before the first interviews were conducted. The major assumption of phenomenology is that knowledge of social facts is best attained when the researcher gets inside the natural setting and attempts to understand the phenomenon as the subjects do. Phenomenology intertwines the observer with the phenomenon (Duffy, 1985). Because the researcher had a specific interest in families with children who have diabetes, and had some expertise and possible preconceived ideas regarding the phenomenon to be studied, the practice of bracketing (Munhall & Oiler, 1986; Sandelowski et al., 1989) was used. Instead of using a priori or preconceived ideas about the phenomenon to be studied, the researcher sought meaning of the phenomenon from the participants' perspective, and data were collected and analyzed in the natural language of the subjects (Duffy, 1985).

Data Collection Procedure

Although the process of data collection will be discussed separately in this section, it should be noted that no clear line between data collection and data analysis generally occurs in qualitative research (Munhall & Oiler, 1986). For this study the two processes were intertwined, and data was analyzed throughout the data collection period.

Data were collected through a series of in-depth, unstructured or minimally structured interviews (Sandelowski et al., 1989), conducted in the privacy and comfort of the participant's own home. Non-directive trigger questions were used, for the most part, in order to elicit "informant-generated questions" (Evaneshko & Kay, 1982, p. 52). However, a set of sample questions was developed for the purpose of...
providing a loose structure for the initial interview (see Appendix B for sample questions). These questions were constructed using the popular arena of Kleinman's (1978) health care system's explanatory models as a guide. This arena encompasses the family context of sickness and care, and includes the parents’ beliefs, choices, decisions, roles, relationships, interactions and subjective experience of caring for their young child with diabetes. The content of the questions arose from both the available literature reviewed in Chapter Two, and from the researcher's prior experience of working with diabetic children and their families.

The sample questions (Appendix B) served only to initiate interaction with the parents and not all questions were asked of every participant. Indeed, the researcher found that once rapport was established with parents and data collection had begun, the participants in this study required little prompting in order to paint a vivid, verbal picture of their perceived experience.

During the initial interviews, the researcher attempted to create an environment of mutual respect and understanding, where the participants felt comfortable and openness and trust was quickly established. Taking a small gift for the infant or toddler with diabetes and any siblings helped the researcher to develop a friendly and trusting relationship with the young children in the family. This also initiated a short period of conversation and "play time" that reduced any stress or apprehension on the part of the parents.

Each of the families visited by the researcher offered tea or coffee and refreshments prior to commencement of the interview. This appeared to have been planned in advance and formed an important aspect of the family's welcoming the researcher into their home and into their lives. During this period of socializing and sharing, the researcher collected demographic information and addressed any questions or concerns regarding the study. Parents spoke freely during this interlude and shared many experiences that were not always repeated during the taped interviews.
Because these parents all had small children and excessive demands in their life, interview times were limited to approximately one hour. However, since the researcher was familiar to most of the families participating in the study, time was also set aside to answer questions and observe parents giving insulin or performing blood glucose monitoring on their child if the family so requested. The child’s cooperation or problems during these procedures was a source of pride or concern for these parents, and data collected from interactions and explanations during these question or observation periods added depth and richness to the parents’ accounts, and were captured in field notes.

Creating a comfortable environment was an important aspect for these parents, who had openly expressed their desire to share their experience. For example, the first interview with one family was conducted just two weeks following the birth of the second son. The father had taken time off from work to participate in the interview, because he felt it was important not only to support his wife, but also to provide a father’s perspective. When the researcher arrived at the home, both parents were exhausted, but fairly relaxed. The mother had just nursed the new baby, who was sleeping, and the father had settled the two-year-old with diabetes down for a nap. However, prior to beginning the taped interview the new baby awoke crying. This caused considerable stress and anxiety for both parents, who had planned so carefully for the uninterrupted interview time, and expressed genuine concern about the disruption. To ease the situation, the researcher offered to comfort the crying infant. The baby soon settled and slept in the researcher’s arms throughout the interview. The father took charge of operating the tape recorder and the mother relaxed enough to share her experience. During the course of the interview, the toddler with diabetes awoke. It was necessary to stop the tape recorder while the parents performed a blood test and provided a snack for their child. The toddler then settled on his mother’s knee and played with the new toy brought by the researcher until the interview was completed.

Similar incidents occurred in other families participating in the study. Infants awoke from naps or required attention from their parents during the course of the interview. In each instance, the parents
expressed concern about the disruption to the interview, and explained how important they felt it was to share their experience. The researcher took time to reassure the parents, and used the interruptions as an opportunity to observe interactions between the parent and child, and to better understand how the child’s needs were met. These incidents confirmed some of the complexities and multifaceted experiences of caring for a young child with diabetes, as articulated by the parents in the tape-recorded interviews.

The first interview for all families was initiated by the question, "What is it like for you, as a parent, to have a young child under three years with insulin dependent diabetes?" This question was usually followed by the researcher asking, "How would you describe your experience of caring for such a young child with diabetes?" The informant’s own dialogue then generated the next question. However, non-directive trigger questions such as "Why do you think this might be?", "Can you tell me more about this?", "Can you describe why you might feel this way?", or "Could you describe this further for me?" were used either to clarify or confirm what parents had said, or to further the researcher’s understanding of a particular aspect of the described experience. Reflective statements ensured that the accounts were validated as the parents’ stories unfolded. Sample questions (Appendix B) were utilized as a guide to facilitate exploration of particular aspects of the parents’ experience, if those aspects were not discussed spontaneously during the parents’ accounts.

Analyzed material from one interview also influenced subsequent data collection processes. For example, as the data collection phase progressed, areas of concern for the parents were added, deleted or confirmed. Themes that emerged as significant from the perspective of one informant family would be used to facilitate further exploration within those themes during subsequent interviews.

The data were constructed through a series of 14 interviews conducted with the parents of eight families over a five-month period. Eight mothers and five fathers described their experience. When both the mother and father participated in the study, they were interviewed together. Some of the unanticipated
advantages of these joint interviews, such as the parents’ understanding of each other’s feelings and concerns for the first time, will be described in depth during presentation of the analyzed data.

Interviews were tape-recorded. Each lasted from 45 minutes to 1½ hours, and a total of 15 hours, 10 minutes of dialogue were tape-recorded and transcribed. However, many of the researcher’s visits with the families extended beyond the taped interview time, and total contact time with the families approximated twenty-five hours. As previously described, many parents shared significant facets of their experience prior to the tape recorder being turned on. Others remembered significant experiences they had forgotten to share once the tape recorder was turned off. Many parents provided extra information just as the researcher was leaving the house. As a parting gesture, these parents would say, "You know, I forgot to tell you all about this part of our experience, and maybe it is important to your study." The substance of these conversations was recorded in field notes made by the researcher immediately after leaving the interview.

Although Field and Morse (1985) suggest that the presence of a tape recorder might affect the participant’s ability to interact normally during interviews, this did not appear to be a deterrent for the parents in the study. Parents were told in advance that interviews would be tape-recorded and each gave their consent for this mode of data collection. Two mothers did explain that they had never participated in a tape-recorded interview before, and requested a replay of part of the interview in order to hear their own voices. These parents seemed surprised by the ease with which they shared information, and by their lack of inhibition in the presence of a tape recorder once the interview had begun. Another mother explained that she had done a lot of taped interviews with medical students and consequently felt comfortable with the procedure. She explained it this way:

"Well, you know, I have done a lot of these types of interviews with medical students so that they can practice interviewing skills and listen to themselves afterwards. I do this through a friend. However, I’ve never talked about ‘G’ [toddler with diabetes] before, so this interview will be very good for me, very therapeutic. It’s good to talk about your own child."
Most families in the study appeared to forget all about the tape recorder once the interview was in progress. There were no requests either to stop the tape recording or to erase any portion of the conversation. When parents were informed that the tapes would be erased immediately following the study, many of the participants requested a copy of the interview before it was erased. These parents wanted to retain the taped conversations, which they felt would be interesting to listen to later. They wanted to compare their early experience with their experience in the future. Some parents thought the young children with diabetes might benefit from listening to the tapes when they were older.

None of the parents suggested that the presence of the tape recorder had any adverse effect on their ability to discuss their experience. In one instance, a mother did require reassurance that the tape would not be listened to by hospital staff in the emergency and intensive care units. This mother had vividly described incidents that occurred when she was experiencing stress and emotional breakdown at the time her toddler was diagnosed. She had blamed hospital staff for much of her stress, and explained that she was not in total control of her emotions at that time. During the course of another interview, a mother described an extremely sensitive experience shared by her husband and herself immediately prior to, and just following the diagnosis of diabetes in their young child. Because her husband was not present during the taped interview, this mother asked that the information she had provided be used only with the strictest confidentiality and anonymity. She tearfully confided that her husband might not feel comfortable about the intimate information she had shared, but that this information might help nurses to better understand what parents go through. In some of the interviews where both parents were participating, conflicts due to differing values, goals and expectations of the parents were often exposed and discussed. In these instances, the parents generally asked the researcher if other participants in the study experienced similar frustrations, anger and conflicts. Many parents used the forum of the interview to better understand each other’s perspective, and their verbal interactions added to the depth and richness of the data.
Most participants in the study described how important and how therapeutic it had been for them to share their experiences. As one father explained:

"It's the first time we've really talked about this, about how we felt, about how we feel now. It's like a big burden has been lifted because someone bothered to listen to our story, and someone brought us together to listen to each other. I think we have benefited more than you [researcher], we understand each other better. It's been so therapeutic, so enlightening, I hope we provided you with the information you needed too!"

Other parents were concerned about their ability to provide the right information for the study. One parent asked:

"Is this what you want to hear? Is this really important? Am I describing our lived experience? It's important to me as a parent, but is it what you are looking for?"

When assured by the researcher that this was indeed important and interesting information, the parent relaxed and explained:

"You see, most people are not really interested in how we manage, not anymore anyway, they tend to back off, it's too complicated for them, they are afraid of everything we have to do ... so it's good to have someone to listen, it's good to be able to share our experience and to know it might help some other families too".

Another valuable source of data was dialogue shared with parents over the telephone during the course of planning and arranging interviews. Significant facets of their experience were often described by parents during these conversations. Some parents also used this method of communication to call and describe a new experience that had not been discussed during a tape recorded interview. Telephone dialogue was also used by the researcher to clarify, confirm and validate beginning conceptualizations with the parents of one family when a second interview could not be arranged. Field notes were recorded following all telephone conversations.

The original intent of the researcher was to conduct first interviews with all eight families in the study prior to beginning any second round interviews. This would provide the opportunity to look for common themes across all the parents' accounts before proceeding with clarifying, expanding and
validating beginning conceptualizations. However, sequencing of interviews deviated slightly from this initial plan.

First interviews were conducted with six of the eight families over a relatively short time span of four to five weeks. However, due to an intervening Christmas and New Year vacation session, interviews with the two remaining families were arranged for dates two or three months after completion of the first six interviews. During this interim, analysis of data from the completed interviews provided the researcher with some beginning conceptualizations of the parents’ articulated experiences. This time of reflection also resulted in a more specific focus for the investigation, and second round interviews used to clarify, expand and validate emerging themes, were conducted with two of six families already interviewed.

Although this process of data collection would appear to exclude the two remaining families from contributing to the data that shaped the researcher’s beginning conceptualizations, this was not truly the case. In fact, the depth and richness of these parents’ accounts complemented in every way the accounts provided by the first six families interviewed for the study. Establishing rapport and interviewing the parents of these two families for the first time so late in the data collection ultimately proved to be an advantage. While relating their own vivid stories that contributed to the variability in data, these parents also spontaneously expanded on and validated many of the beginning conceptualizations of the researcher. Their accounts also clarified themes emerging from significant statements made by other parents in earlier interviews.

Although unplanned, the fortuitous timing of these parents’ accounts lent credibility to the initial interpretations and tentative analysis of previously collected data. They also clarified and guided the open-minded, enquiring approach required by the researcher going into the second round of interviews with the remaining families.
Analysis of Data

As previously described, data analysis intertwined with the data collection process, and the two processes ran concurrently until the data collection was complete. During this time, data were categorized and clustered into related concepts and themes. However, relabelling and reorganizing of concepts and categories occurred many times throughout the analytical process. Once data collection was complete, the analysis entered a final stage of bringing together and confirming previously developed ideas (Sandelowski, 1986).

Throughout this study the researcher also utilized the techniques of bracketing and reduction mentioned earlier in this chapter. Bracketing involves setting aside what the individual thinks she or he knows about the experience in order to achieve reduction (Munhall & Oiler, 1986). Reduction is a process of choosing to perceive from the participant’s vantage point. "It is a reflective turn back toward experience with a conscious effort to bracket what is known, and a creative process of intuiting and analyzing human experience" (p. 82).

Data from the parents’ articulated experiences were subjected to the following treatment. Tape-recorded interviews were transcribed verbatim. Because the researcher transcribed all but one interview herself, she quickly became familiar with every facet of the data. Audible cues captured on the tapes but not transcribed were noted by the researcher, and taped interviews as well as transcripts were shared with members of the thesis committee.

Transcripts from each interview were subjected to phenomenological analysis using Colaizzi’s steps as outlined in Munhall and Oiler (1986). Giorgi (1975), who described central themes, structure and style, also influenced analysis and interpretation.
Stage I Analysis

1) All transcripts were read in their entirety in order to acquire a feeling for the subject’s descriptions. Audible cues captured on the tapes were considered during the reading of the transcripts.

2) A second and third reading were conducted and significant statements about the phenomena were extracted, and categorized.

Stage II Analysis

3) Meaning units were then formulated from each of the significant statements. The meanings arrived at were inextricably connected to the original descriptions of the parents.

4) Clusters of themes were organized from the aggregate formulated meanings allowing the emergence of themes common to all parents’ descriptions. These clusters of themes were then validated and discrepancies between and/or among clusters were noted. The researcher returned to the subjects at this point for a second interview to verify meanings or elements, and to clarify, expand and validate the researcher’s conceptualizations.

5) Significant statements of parents captured and recorded in field notes were also used for reference by the researcher when confirming and clarifying emerging themes and concepts from the parents’ described experiences.

Stage III Analysis

6) An exhaustive description of the phenomenon was then formulated through integrating and synthesizing the results of the analysis. The exhaustive description, including verbatim quotes from the participants’ accounts, summarized the essential structure of the lived experience of parents who are caring for a young child under three years with diabetes. A summary of the exhaustive description was provided.
7) The validation process continued throughout the entire data collection and analysis phase.

8) Because it was the researcher's intent to present data which enhance understanding of the shared experiences of parents participating in the study, analysis involved constant comparison among the participants' accounts.

**Auditability and Confirmability**

The conventional scientific criteria of rigour (reliability and validity) used in quantitative research is not applicable to a qualitative design. Instead, the criteria of rigour for achieving credibility and ensuring the truth value and applicability of a qualitative study is described as confirmability (Sandelowski, 1986).

Several measures to ensure rigour of this study were adopted. Auditability was a criterion of rigour. Auditability is achieved when the researcher leaves a clear "decision trail" concerning the study from its beginning to its end. This involved the members of the thesis committee clearly following the "decision trail" left by the researcher, and ultimately arriving at similar or comparable meaning units and themes using the same data, and understanding the researchers' perspective and situation (Sandelowski, 1986). Auditability is specifically achieved by a clear description, explanation and justification of how the researcher became interested in the subject matter of the study, how the researcher viewed the topic being studied, the specific purpose(s) of the study, how subjects and pieces of data were included in the study, how the data were collected, the impact that the researcher and participants had on each other, the nature of the setting(s) in which the data were collected, how data were reduced, transformed, interpreted, and presented, and the specific techniques used to determine the truth value and applicability of data (Sandelowski, 1986, p. 35). Auditability was considered when writing the final report.

Other strategies used to achieve credibility and fittingness of the study included prolonged contact with the parents, during which time continuous validation of data was sought. These strategies included
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checking with participants in the study and with experts on the thesis committee for representativeness of data and fit between themes or meaning units, and seeking advice and guidance from these experts on the evolving themes and on analysis and interpretation of data. Confirmability, which is the criterion of neutrality in qualitative research, was sought when auditability, creditability and fittingness of the study had been established (Sandelowski, 1986, p. 35).

Internal validity, or "fittingness" with subjects' accounts occurred when the results of the study presented a faithful description of the experience of caring for an infant or toddler with diabetes that could be immediately recognized by the parents as part of their own experience (Sandelowski, 1986, p. 35). An interesting example of this "fittingness" occurred when parents from four different families in the study independently described caring for their toddler with diabetes as caring for 1½ or more children. Each parent described their need to meet the demands of a normal toddler, plus their added responsibility of handling the complexities of the diabetic regimen for their child. Other parents in the study immediately recognized and validated this description as part of their own experience.

Summary

The phenomenological method of qualitative research used to study the experience of parents caring for an infant or toddler with diabetes was described in this chapter. A brief introduction to the method was provided. This was followed by a description of how participants for the study were selected. Criteria for selection, selection procedures, and demographic information used to describe the characteristics of the participants were included.

Procedures used for protecting human rights were described in this chapter, and the role of the researcher was explained. The processes of data collection and data analysis were discussed in detail. Although it was noted that these two processes intertwine and occur concurrently in qualitative research, each was described separately to enhance clarity of the methodology. An in-depth description of the
process used for conducting the tape-recorded interviews was provided. Methods used for transcribing the interviews, interpreting results, and clarifying, validating and expanding concepts and themes were discussed. Auditability and confirmability, used as criteria to ensure rigour of the study, were described. The chapter concluded with an example of "fittingness" of the results. This occurs when findings of the study present a faithful description of an experience that can immediately be recognized by parents as part of their own experience.
CHAPTER FOUR

Findings: Parents’ Perceptions of Their Experience

Introduction

This chapter will present the parents’ accounts of their experience of caring for an infant or toddler under three years with insulin dependent diabetes mellitus. Because these infants and toddlers generally present with an abrupt progression of acute diabetic ketoacidosis, then face a lifelong chronic condition, the impact of both the initial and long-term effects of their child’s diabetes were described by the parents. Each parent presented their experience in a unique way, and each made a special contribution to the data by offering a different perspective of the experience according to family circumstances, beliefs, values and personal philosophies. Each infant and toddler with diabetes was also unique, with his or her own characteristics, personality and individual ways of dealing with the situation. Thus, a kaleidoscope of emotions and realities were described by the parents. However, despite considerable variability in data, certain themes did occur repeatedly across all the parents’ accounts.

Because it is the intent of this study to present data which enhance understanding of the shared aspects of the parents’ experience, this chapter will be organized according to common or unifying themes that emerged from the parents’ accounts. Experiences described by the parents will be organized into three distinct phases, which are linked to a timeframe and were identified by the researcher as the data were analyzed and compiled. Each phase will be organized into three major conceptual categories containing common themes extracted from significant statements made by the parents during the interview process. The three distinct phases and three conceptual categories in each phase will provide a structural framework for the parents’ accounts, and will be described in more detail later in this introduction.

There is an old saying which proclaims that "it is impossible to truly understand another person’s experience until you have walked a mile in their shoes". This study was designed to explore and to
describe the parents' experience, and to provide insight and understanding into the phenomenon from the parents' perspective. Consequently, this chapter presents data perceived from the parents' vantage point and, as such, provides the means through which to "walk a mile or more in the parents' shoes."

Phases of the Experience

From the articulated experiences of the parents, related in the tape-recorded interviews, it became apparent to the researcher that families go through three distinct phases in the process of coping with diabetes in their infant or toddler. These phases appear linked to a series of events occurring in the parents' lives, and follow a timeframe described by all the families interviewed for the study.

The first phase of the experience began with the initial crisis related to the diagnosis of diabetes in their infant or toddler. This phase included the acute onset of diabetes, the young child's admission to hospital, the parents' experience in emergency departments and intensive care units, and the events surrounding learning how to manage their young child's diabetes in the hospital setting. This emotion-laden and vividly recalled sequence of events marked the beginning of the parents' perceived experience and was the point at which most parents began their accounts.

The second phase of the experience began when the infant or toddler was discharged from hospital and the parents began the task of caring for their young child with diabetes at home. The parents' perceptions of their experience of coping with this often stressful, frightening and frustrating situation spanned a period of six to seven months post-diagnosis, and for some families lasted even longer. Parents described this time as being one of strictly surviving rather than living. A time when they felt riveted to a totally inflexible regimen that ruled their very existence. Only the passage of time, and the parents' ability to gain knowledge and understanding of their child's condition, allowed them to move into the third phase of the experience.
The third phase was related to the process of adapting and incorporating the infant’s or toddler’s diabetic management regimen into family life over the long term. Parents described this phase as being less stressful. They had learned to relax and to incorporate vigilance and flexibility into their child’s daily care. Increased knowledge and understanding, and familiarity with their child’s diabetes, served to empower parents and allowed them to take control. However, new stressors and recurring or sustained struggles were vividly described by parents, and these evoked emotional responses and reactions that had to be dealt with. Increased confidence in their own abilities, teaching others and accepting the realities of their child’s long-term condition were all strategies that helped parents manage their situation. Because the beginning of this third phase of the parents’ experience was not as clearly defined as the beginning of either phase one or two, an explanation of the transition from the parents’ perspective will be provided in the introduction to this phase. Significant changes in attitude that justify the parents’ belief that they had moved into a new level of understanding and acceptance of their child’s condition will be described.

Much of the variability in data from the parents’ accounts can be directly linked to events such as the length of time since diagnosis for the young child with diabetes, or the age of the infant or toddler when the parents were interviewed. One of the fortuitous advantages of collecting data from parents over a five-month period was the ability of the researcher to identify, then validate and confirm the presence of these three distinct phases in the parents’ experience. Interviewing two families for the first time late in the data collection process (see Chapter Three) also helped the researcher to clarify and expand on this concept. These parents described their experience of recently and intuitively moving into the third, adaptation phase of caring for their young child with diabetes. However, they could also vividly recall, relate and compare their earlier experience during the first two phases.

The three distinct phases linked to a timeframe and a series of events occurring in the parents’ lives will be discussed consecutively in this chapter, as conceptualized facets of the described experience.
Parents’ Perceptions of Caring for Infant Diabetes

Conceptual Categories Significant to Each Phase of the Experience

Three major conceptual categories which seem most significant in terms of how parents understand and describe their experience have been termed "perceived stressors", "reactions and emotional responses to identified stressors" and "coping strategies employed by parents to manage the situation". These three broad conceptual categories span all three phases of the parents' articulated experience, and will be introduced as each phase is presented.

When describing the perceived stressors that impacted on their lives due to their infant's or toddler's diabetes, the parents also identified their reactions and emotional responses to these stressors and the strategies employed to deal with stress and to manage the child's condition. Thus, the parents' accounts described the complex and multifaceted nature of caring for such a young child with diabetes. The perceived stressors, the responses to these stressors, and the actions taken to manage the situation were interwoven through the parents' accounts and were related to their individual perception of the experience.

Although each family articulated their experience in a unique way, it is the intention in this chapter to present data which enhance understanding of the shared experience of all families in the study. Consequently, the researcher has extracted significant statements from each parent's story and regrouped these statements into themes which are composites of data from the combined experiences of all families. Each theme will be organized under one of the three major conceptual categories identified, and then placed within the appropriate phase of the parents' experience.

Because the three distinct phases of the parents' experience occur on a continuum, several prominent themes persist to one degree or another throughout all three phases. Many of the stressors identified by parents involved their struggles with giving injections, getting the child to eat, attempting to stabilize their infant's or toddler's blood sugar and dealing with the constant fear of hypoglycemia. These and other commonly-recurring themes from the parents' accounts will sometimes be described as
a continuum through two or more phases to avoid repetition. When this occurs, an explanation will be provided in the researcher's narrative.

In this chapter, each phase of the parents' experience will be introduced and summarized, and the themes within each conceptual category will be identified and explained. Verbatim quotes from the parents' accounts will be used to illustrate the researcher's narrative under each theme. An outline depicting the framework of the themes organized from the parents' accounts can be found in Appendix C.

Capturing Emotions

It has been suggested that the written word can never fully capture the emotion expressed during a spoken interaction. The researcher admits that audible cues provided by parents during the tape-recorded interviews will be difficult to capture in this presentation of their accounts. During some interviews parents wept when attempting to describe particularly painful or disturbing experiences. Other parents were often close to tears or displayed emotions of anger, frustration, sadness, or helplessness in facial expressions. Often periods of silent reflection were required during interviews as parents calmed themselves or collected their thoughts. Some parents required comfort and reassurance from the researcher. Others appeared very calm, relaxed and self-assured. In presenting the parents' stories, an attempt will be made to provide a true and vivid verbal picture of the shared experiences.

Although the initial crisis involving the diagnosis of diabetes in the infant or toddler spanned a relatively short period of time, it was recalled and described as an acutely stressful experience by most of the parents in the study. Consequently, the parents' accounts will begin here.
Phase One: The Diagnosis of Diabetes

Because the infants and toddlers involved in this study were so young when they developed diabetes, the time of diagnosis and the initial crisis of the hospital experience was vividly recalled by most of the parents. Indeed, because of the relatively short time since the child’s diagnosis for most parents in the study, the recent experience of events culminating in their child’s hospitalization were recounted with deep emotional reactions. It appeared necessary for all parents to start their accounts at the beginning in order to justify their later responses and actions. Despite unique and individual ways of describing their experience, certain themes remained consistent across all parents’ accounts.

Although these themes can be partially organized under the three conceptual categories of "perceived stressors", "reactions and emotional responses to perceived stressors", and "coping strategies employed by parents to manage the situation", it must be noted that some overlap and intertwining of conceptual categories and themes occurs when presenting the parents’ accounts of this phase of their experience. Because the critical time involving diagnosis of diabetes in their young child resulted in disequilibrium, extreme anxiety and disorganization for most families, the parents’ initial reactions and emotional responses to the perceived stressors were inextricably interwoven throughout their accounts. Consequently, many of the parents’ perceived stressors and emotional reactions to these stressors will be discussed simultaneously throughout both conceptual categories.

Parents also described some of their initial behaviours as reactions to shock, exhaustion and feeling totally overwhelmed by the situation. Consequently, although some of these behaviours could also be identified as coping strategies used by parents during this initial phase of their experience, they will be presented as reactions or responses to perceived stressors for the purpose of this study.
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Perceived Stressors

The initial stress for parents began with the diagnosis of diabetes in their child. Because most infants and toddlers generally present with an abrupt progression of acute diabetic ketoacidosis, they are extremely ill when first admitted to hospital. Consequently, the experience of the diagnosis and hospitalization for the child was extremely stressful for all parents in the study, and many parents described these experiences as devastating.

The events that created the most stress for parents were receiving the diagnosis, the hospital experience and learning the diabetic management regimen. Common stressors related to these events included the acuity of their child's initial condition, the multiple invasive procedures required, the shock of a lifelong chronic condition in their child, and the complexity of the management regimen required to maintain their child's life and health. Parents' descriptions of a buildup of stressors also reveals the magnitude of the stress experienced by these families.

Receiving the diagnosis

Initial reactions to their child's diagnosis were generally those of shock, disbelief and devastation. The following quotes illustrate the impact of the diagnosis on parents.

One parent who had never heard of diabetes in a child described his experience as frightening and one of absolute disbelief. He explained:

D: Well, we were just ... we were ... well, it was the disbelief. I didn't want this to have happened to my son. It was frightening.

NOTE: In the following accounts,

M = mother (mom)
D = father (dad)
R = researcher

When initials or names are cited in the accounts, they are fictitious.
Other parents described how their life had been turned upside down, and feelings expressed were those of shock and being stunned. The mother began the description this way:

M: I want you to know that when ‘R’ was diagnosed, I was absolutely devastated. I couldn’t face it all.

D: You know it falls like a thunderbolt out of the sky, right onto your house - DIABETES - and you think ... (mom taking up the sentence)

M: Why me! Oh! Why him, why us? Oh God! Why?

D: Yes, it’s like this sudden shock. One day everything is going along smoothly, and the next day everything was upside down and we were standing on our heads ... our world changed.

M: We were totally stunned.

Variability in parents’ perceptions and reactions to the diagnosis in their child resulted from their past experience with diabetes. For some parents, their past experience helped them to be more calm, while for others, their past experience caused them to be more frightened, as the following parent relates.

R: You said you had an inkling that ‘R’ had diabetes. Do you know someone else who had a child with diabetes then?

M: Yes, ‘H’s [dad’s] niece who was visiting from Australia. We had watched the insulin and the blood testing and everything, and also the worry that the parents had. I remember one day she wandered off and was moody and irritable before she left and the parents were frantic. We didn’t fully understand then, but we could never forget their panic. Never! When we heard the diagnosis for ‘R’ we felt the same panic, ... the same fear.

Other parents had no experience with diabetes, which in some instances led not only to a delay in diagnosis but also to the parents being very frightened, as the following quote indicates:

M: It was awful really. From January to March ‘G’ had been irritable, dragging around, hanging around me, miserable, and I was getting so angry with her. I thought it was the "terrible two’s" coming early because she wasn’t even two ... And I used to get mad ... I thought it was me that was having a breakdown, that I couldn’t cope, that I needed therapy. I almost went to the doctor for myself. I didn’t once think it was ‘G’ who was sick. She was very thirsty because she started drinking from a cup. I thought how smart she was not to want a bottle anymore ... then it was all the peeing ... she’d lie on the chesterfield and she’d be soaked all through her diaper and the furniture ... I thought it was all the drinking, but I should have guessed. You see, I’ve always been borderline hypoglycemic and I thought one day I might develop diabetes so I read all about it ... but I couldn’t see it in another person, not in ‘G’, not in my own child ...
R: I understand.

M: After almost three months of her being irritable and thirsty, etc.; we took her to the doctor ... she was very limp ... not my little girl at all ... can you imagine we took so long before having her seen ... then the doctor said to take her immediately to emergency - right away, I couldn’t believe it ... I was sure she had leukemia or something terrible like that, I thought she might die. In the emergency they put up all the I.V.’s and things. I was very, very scared.

Other parents, whose young child had showed few symptoms prior to diagnosis but who became acutely ill quite suddenly, explained the initial impact of their child’s diabetes this way:

D: Yes! to begin with you are in total shock, total denial. This cannot be ... not us ... not our child ... what did we do to bring this on ourselves, on our child ... he was so healthy, so happy, so precious, our only son ...

These parents described feelings of denial, while others experienced horror, terror, anger and sadness. When her young son lay motionless one mother began to feel totally overwhelmed by the experience. She expressed her reaction to the initial crisis this way:

M: I was horrified and terrified. I’m afraid of hospitals and I couldn’t believe this was happening to our son. He just lay there with tubes and monitors everywhere ... I was angry and sad and totally overwhelmed by the whole experience.

For another family, blocking out the experience appeared to be a strategy used by the parents to eliminate some of the initial stress, shock and disbelief that was almost unbearable. In this family, where the infant was only five weeks old at the time of diagnosis, all the parents could say was:

D: It was hell, an absolute hell, we were so stressed out and so absolutely in shock that we hardly remembered a thing. Our baby was so sick we were convinced he would die so we just blocked it all out.

The mother of this infant explained her reaction:

M: Oh! it’s so difficult to go back. I was so lonely then ... so all alone with this small baby with diabetes ... it’s almost a blur ... something I’d rather forget.

R: It’s hard to go back isn’t it?

D: Yes, but there was so much stress then, incredible stress, it’s like this black wall came down and blocked it out.
These parents then went on to describe current issues, concerns and stressors in their lives which will be discussed later. However, just by providing a description of their efforts to block this experience out, these parents had identified feelings of utter loneliness, shock and incredible stress when their infant was diagnosed.

Previous experience with diabetes in the family could also affect the parents' perceptions of their child's condition. One mother's stress was heightened because she described her knowledge of some of the long-term implications of the disease when her toddler was diagnosed:

M: Well, it had a major impact on us. But I think I secretly knew before he was diagnosed and I lay awake all night thinking it was diabetes. You see, my father had diabetes; he was diagnosed in his 50's. He's on insulin now but his condition is deteriorating. All I could do was imagine all the complications and I prayed, "Oh! God, don't let it be diabetes ... not in my son ... he's so little." But the next day we went to the hospital and it was diabetes. I wondered ... "What has he done to deserve this ... what have we done to deserve this?"

In contrast to most parents one mother initially viewed her son's diabetes quite calmly. Having a niece, a nephew and a mother with diabetes helped to ease the situation. The mother explained:

M: In the beginning I think I managed fairly well. You see my brother has two children with diabetes and one was only two years old when she was diagnosed. My mom also has diabetes so somehow I almost expected it ... My mom saw the symptoms in 'A'. She said you must take him to the hospital. So we caught it very early and 'A' wasn't as sick as most little children are. His blood sugar was 46 [mmol/L] and he did have ketones, but not ketoacidosis. So in the beginning it wasn't as overwhelming. I thought it was only one injection a day. Now I realize I didn't understand at all. I knew nothing about diabetes management.

For another mother, who had gestational diabetes when pregnant with her young son, the initial shock was tempered by her belief that the diabetes could be "fixed" and would go away. Because her gestational diabetes had been transient, she had no reason to believe her son's condition would not be the same. She described her initial reaction, then went on to explain her reactions of shock and disbelief when she was informed that her toddler's diabetes would be a lifelong health problem.

M: Even in the hospital I didn't really understand. You see, we were in Emergency ... Then this intern came and said 'C' had diabetes but I still didn't really understand. I thought it would just be a medicine to fix it and we could then go home, but then he began telling us this would be a life-long disease and he'd need shots every day for life. It was a shock as you can imagine. You see, I'd had gestational diabetes with him and I needed insulin just for a
month, then it was gone. I thought his would be the same. I couldn’t believe such a young child could need insulin for life. The stress and disbelief was incredible.

Another mother who had a medical problem of her own described the diagnosis of diabetes in her six-month-old as being less of a worry than her own blood clotting problem. She described her ultimate fear as being that of her son bleeding to death, and not fear of him having diabetes. She explained:

M: When we got to the hospital and they said diabetes I thought poor little beggar as if he doesn’t have enough to put up with. You see I have this blood clotting problem and ‘S’ had inherited the gene, and I was more worried about that, more worried about him clotting or bleeding to death ... so I thought diabetes ... no big deal.

Although this mother initially considered her infant’s diabetes to be no big deal, this was not the case with the majority of parents in this study. As the magnitude of the diagnosis began to dawn on some parents, they contemplated the future for themselves and for their child. The realization that their child had a lifelong illness left parents feeling trapped. Because they knew their child would be dependent on them for their life and sustenance for many years to come, parents realized that life would never be the same. They wondered if they could ever be happy again, and also questioned their own ability to care for a child with complex needs. The beginning realization of both the initial and long-term needs of their child was described as a total nightmare by most of the families.

One of the mothers explained:

M: When I heard it was diabetes, I knew ... just knew it was like a sentence ... I’d be trapped like a prisoner sentenced to a life of insulin injections, testing and diet restrictions. With such a young child, who would be totally dependent on me for her very life and existence for so many years, I knew I was trapped, and that things would never be the same again.

Another mother described the devastating realization this way.

M: Yes, and I remember thinking I can never truly be happy again because always in the back of my mind was that realization that my son was diabetic, that all our hopes and dreams were in a bubble that had burst and that we’d never laugh or be the same again.

The initial crisis experienced at the time of their child’s diagnosis was only heightened by the hospital experience, and the procedures required to save their infant’s or toddler’s life and restore health.
Descriptions of the stressors, frustrations, fears and struggles encountered by parents during their child’s hospitalization constitute the next theme.

The hospital experience

As parents related their accounts of the first few days of their child’s hospitalization following diagnosis, they identified a number of stressors with which they were faced. These included the taking of blood from their infant or toddler with diabetes, the testing of blood sugar levels, the need for intravenous solutions, the hospital environment which included the tubes, monitors and invasive procedures, the need to give insulin, their own lack of understanding about diabetes, the amount of information that had to be learned, a lack of privacy and no time to be alone to think or to grieve, and the exhaustion of sleeping beside their child in the hospital environment. Each of these stressors will be described as part of the overall experience related in the parents’ accounts.

Taking blood from the infant or toddler was an event that resulted in extreme stress for most parents. Because most infants and toddlers were acutely ill at the time of diagnosis, they required constant monitoring of blood sugar levels in order to determine fluid replacement and insulin requirements. Most children were initially cared for in the emergency or intensive care units, and the constant monitoring and the invasive procedures required to obtain blood from the child were a source of intense stress for most parents. The following parents’ accounts graphically illustrate some of the fears, frustrations, sadness and anger directed towards lab technicians who were required to take blood from the child. The parents also described feelings of helplessness, and being out of control, which culminated from the overwhelming stress of the situation. A mother explained:

M: ‘G’ of course was very sick ... she went to that I.C.U. place where it’s all open and all those nurses and the lab. people doing blood tests every 5 minutes on her poor little fingers. I couldn’t stand that ... her fingers were blue ... Why couldn’t they take it from an arm vein or the I.V. or something ... then a lab. tech. dropped a vial and I flipped. I shouted and got very upset ... The nurse got upset because ‘G’ kept crying ... I had to go out and the nurses comforted me ...

One father who had little experience with hospitals explained his reaction this way:
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D: All the nurses and technicians. They kept trying to take blood out of his arm and I’d never seen blood taken before and here I was trying to hold ‘D’ down on a hospital gurney while everyone poked at his little arms or his fingers. The lab. techs. were using those sharp things that actually cut into his finger and suddenly I was feeling anger and hatred towards the lab. techs. You don’t want to feel that way but you do. He’s so little and didn’t understand all this and we became very protective of him. During that first week, every time he saw a lab. tech. coming he started to scream.

This type of hospital experience seemed to impact dramatically on parents because yet another father angrily explained:

D: It was total disbelief ... We got angry with the doctors ... we thought they didn’t know what they were doing ... you see they were taking all this blood out of his arms ... out of his fingers ... and although I’m usually quite a rational person I felt sick. Why were they doing this. They tried to explain ... the nurses ... the doctors ... but I couldn’t listen. We didn’t understand ... not like we do now. I think we were a lot of trouble, very bad parents, but we felt helpless and out of control.

Because the diagnosis of diabetes is unexpected, few parents had time to prepare themselves for the hospital experience. Parents found themselves sleeping beside their infant or toddler and the lack of sleep contributed to exhaustion, and increased the parents’ level of stress, as the following comment illustrates:

M: We took it in turns to sleep beside her or stay with her. We never left her for a moment day or night. But as you know for the first few days ‘S’ was in isolation with a rash. We couldn’t even leave the room, and she was so whiny and demanding. And when the nurse came to teach us how to do things ‘S’ was still there, clinging to us ... crying ... We were totally and utterly exhausted.

Despite feeling exhausted and totally stressed by the events surrounding their young child’s diagnosis and hospitalization, parents were also expected to learn how to manage the diabetic regimen. The magnitude of the tasks of learning how to care for their child were vividly described by parents. These stressors constitute the next theme constructed from the parents’ accounts.

Learning the diabetic management regimen

The impact of the child’s required management regimen was described as a major source of stress by all parents. The necessity to learn how to give injections, how to do blood tests, and how to control the diet were stressors that impacted on parents’ emotions in a number of ways.
The mother who had initially described herself as managing fairly well because her brother's children both had diabetes, described her husband's reaction which was totally different from her own:

M: For 'G' [the infant's father] it was a totally devastating experience. He was an emotional wreck, he couldn't handle it. During the teaching with the Nurse Clinician he couldn't even look at the injections or the blood tests. He'd turn absolutely white, almost faint and have to leave the room. He is also a gourmet cook, so when the Dietitian began to talk about food restrictions he just broke down. He couldn't take it. So I had to learn it all myself, and suddenly I realized the implications for us all, our lives would change forever.

When describing blood testing and the need to give insulin, the impact of her son's diabetes was realized even more by this mother:

M: Now I had trouble poking those poor little fingers, they were so tiny and bled and bruised so easily. My brother never had to do this for his child so it was a shock and it was all up to me. For ‘A’ it wasn’t as bad as the insulin. But those things really hurt you know, when I tried it on myself I was shocked, it really hurt!

For some parents, the need to perform invasive procedures such as injections or blood tests on their child evoked physical symptoms such as feeling faint or feeling ill. Parents who practised procedures on themselves before injecting insulin or pricking their child's finger to obtain a blood sample described how painful each procedure was. In particular these invasive procedures evoked stress responses from parents when bruising or excessive bleeding occurred.

One mother explained her fear of needles, and how the hospital experience impacted on her future emotions. Although it had been 14 months since her young son's diagnosis when the interview was conducted, this mother still vividly recalled the impact of trying to give her first injection:

M: Oh! it was so very hard; you can't believe how hard it was for me. You see I was terrified of needles then, in the hospital I mean, and the fear has never gone away.

It really all started when the nurse said we couldn't go home until I'd done a shot in 'C's stomach. He was so little and I was so scared, and he had no fat on his stomach. But 'S' [dad] said "Come on, just do it" because we all wanted to go home. So I did, but I'll never forget it. It was so traumatic for us both, it scared me so much.
The previous stress of giving injections to herself also haunted one mother. Although this parent was an R.N. and comfortable with giving injections to others, it was different when considering the magnitude of giving injections on a daily basis to her six-month-old son. She explained:

M: It was so hard, so traumatic. I'm used to injections, I give myself injections every day ... but oh! God, it was different giving it to my own baby ... he was only six months old and I wasn't quite prepared for that.

For other parents, the total experience of learning to manage their child's diabetes was fraught with anger and frustration. Stress resulted from a lack of understanding the disease as well as the need to learn all the necessary procedures. An added stress was a lack of privacy, a lack of time to be alone, to relax, or even to comprehend what was going on. The following accounts emphasize these stressors:

D: Well it wasn't just the finger pokes, it was everything else. We found it difficult to understand the disease itself and what was going on. So together with the anger and frustration, we were watching videos, or taking lessons, learning all about the disease and we became so overwhelmed.

R: There is a lot to learn when you are experiencing so much stress.

M: Yes, in fact I think we were too busy because we weren't left alone for a minute to stop and just think and wonder what's going on here. You see, even in the Emergency the day we came in, from morning till night we were never alone. There was someone there all the time and we didn't have a moment to talk or even to think clearly, to understand what was going on. Even when we got to the ward there were people checking him and checking us. I felt like saying, "Please give us just a minute to be alone, to catch our breath, to comprehend what's going on here."

R: It must have been a very difficult time for you.

D: It was. But then again, if we hadn't had all the concentrated teaching day by day, we wouldn't have got out of there and boy did we want to get out, to get home. If only there was a manageable way someone could come to our house to teach us instead so we could sleep in our own beds and relax a bit.

These parents had identified a need requiring nursing intervention. They described a perceived source for reducing stress by explaining that teaching the concepts of management in the home environment instead of in the hospital setting could relieve anxiety, reduce exhaustion and, by so doing, enhance learning.
Other parents described situations in which the young child's behaviour impacted on the teaching situation and became a barrier to the parents' learning. Toddlers who were totally stressed by their own traumatic experience placed excessive demands on the parents. Consequently, parents became too exhausted to learn or comprehend even if support was offered to care for the child during teaching sessions. The child's entire life had been disrupted by the hospital experience and this disruption was reflected in the child's behaviour. The parents described their dilemma this way.

M: Our daughter's behaviour affected our ability to learn and added to our stress. Although we tried to use nap time for the education sessions it didn't work ... you see her whole routine was disrupted, she was only 15 months old and this whole experience was totally traumatic for her. She'd scream even when we were trying to practice injections on an orange ... just the sight of the needle freaked her out...

My Mom and Dad came to help out but she wouldn't go to them ... It was really too much for all of us. There was so much to learn, so much to comprehend ... and we were exhausted ... The nurses were so good and they offered to babysit while we had our teaching, but it didn't work in the beginning. 'S' would just scream. Later, when she could go to the playroom, it was better. We could relax a little, but we never completely relaxed ... ever!

Another father described his experience this way:

D: You are totally overwhelmed, they are telling us all about needles, injections, insulin, poking fingers for blood tests 4 times a day and you are thinking this cannot be, we won't be able to do this, we'll never cope...

You spend all day at the hospital and you become exhausted sleeping on that little bed and you just want to take your child home, but you know you can't until you've learnt all this stuff ... then you realize things are never going to be the same even when you do get home.

Another major source of stress for parents was the stress experienced by grandparents and other relatives. Some grandparents did try to become involved in the learning process. However, they also became totally overwhelmed by the magnitude of the complex management regimen. As one mother explained:

M: My parents visited daily and tried to listen ... but learning all about this was too much for them and for me. There was so much to learn ... they felt sorry for us and for 'S' [toddler] and that made it worse. My sister came but she couldn't even look [at blood tests, etc.] so that just made things worse.
It appeared from this parent’s account that family members who had been relied upon for support in the past were too stressed themselves to offer adequate support during the toddler’s hospitalization.

Although the stress of their child’s diagnosis and hospitalization was compounded by the stress of having to learn a complex management regimen, some parents described an even greater buildup of stressors that impacted on their ability to learn.

**Buildup of stressors**

For many parents the perceptions of their child’s diagnosis and hospitalization were described as a culmination or continuation of a multitude of stresses already being experienced in their lives. When asked about their hospital experience the father of a two-year-old boy explained:

D: I already had a lot of stress at work, and ‘M’ [mom] was just recovering from a bad car accident and then this diabetes. It just doubled the stress, but I think I was so stressed already that the amount of stress I had was so large that this just added to all the rest. ... It was too much on top of the other stresses I already had, so my mind went into shock.

This father described multiple stressors impacting on the family prior to their young son’s diagnosis of diabetes. The added stress of the child’s diagnosis contributed to the father’s distress and affected his ability to function. In another family, the father had just lost his job and the stress of that prior situation made it even more difficult for the parents to deal with their son’s diabetes. The mother explained:

M: Well ‘G’ [dad] had been made redundant and that was bad enough ... but when ‘A’ got sick it was hard on us both ... but unbelievably hard on ‘G’. ... He took it all very hard and had a very difficult time with it all. Of course he was unemployed at the time ‘A’ was being diagnosed and with just having lost his job too, this was far too much for him to handle ... (Mom began to cry)

R: I understand.

M: Well (crying), poor guy, he did suffer an awful lot at the time. He was also very fragile. He couldn’t bear the needle. So all ‘A’s care was left to me (sobbing). ... I had the stress of a husband out of work, a toddler with diabetes, and only me to learn everything alone ... it seemed too much ... too many stresses together.

For another family, the buildup of stressors involved a recent move and a new job for the father. As the parents explained:
D: You know, there is so much frustration over this thing. So much frustration, a lot of anger involved in this, you get so angry because it’s a time in your life when you’re just building your family, just thinking of buying a house or getting a car, and suddenly you are affected by this huge monster called diabetes.

M: Yes ... you see, we were fairly new in town. We’d just moved here, we also had little ‘K’ at home and all the demands and stress of worrying about ‘D’ and being at the hospital with him. We didn’t have anyone out here to take care of ‘K’, so we landed up flying ‘A’ [dad’s] parents out here, but ‘K’ didn’t know them and it was stressful for everyone.

This family also described a stressor related to the care of siblings. As well as recently moving to a new city, this family was obliged to rush their two-year-old son into hospital and abandon the care of their second child. ‘K’ was a six-month-old sibling, and much of the parents’ articulated stress was related to leaving this little one at home in a strange city with grandparents who were virtual strangers.

D: And of course, with a little baby at home, I was so worried about her, could the grandma manage this baby she hadn’t met.

R: How did the grandparents feel, do you think?

M: Well, it was very hard on my family, especially on my dad, because he has diabetes and he could identify all the problems and heartaches this little boy would have.

For this family, the mother also explained how stressful their son’s diabetes would be for his grandfather. The grandfather also had diabetes and was experiencing some complications due to his disease and, therefore, could identify all the problems and heartaches faced by his grandson in the future.

The anticipation of possible complications was also an added stressor for some parents who had prior knowledge or experience with diabetes. One mother described her own stress as well as that of her husband when they realized how much their young son would rely on them for prevention of future complications.

M: We read so much and read all about the complications and of course read that in some people, however well controlled they are, complications can occur. So that really troubled us because ‘A’ is so small ... Then I thought about kidney failure, being on dialysis and all those things I find very frightening, and I had one major emotional attack ... Because I realized ‘A’ was totally reliant on me for his survival ... and yes, I found that frightening.
Parents’ Perceptions of Caring for Infant Diabetes

These multiple stressors experienced by parents were perceived as a combination of prior stressors in the families’ lives, stress related to past experience with diabetes, and the current stress caused by their child’s immediate situation and complex needs. Thus, the parents’ accounts revealed that these families experience several coexisting stressors at the time of diagnosis and hospitalization for their infant or toddler, and that their early experiences were dramatically shaped by these multiple stressors. Overlapping and intertwining emotional responses to these multiple stressors have been described as part of the parents’ multifaceted experience.

Reactions and Emotional Responses to Perceived Stressors

Parents’ perceptions of events surrounding their young child’s diagnosis and hospitalization evoked varying degrees of emotions and feelings. Emotion-laden responses to the situations parents found themselves in included shock, disbelief, fear, devastation, panic, anger, grief, guilt, sadness, horror, terror, worry, stress and sometimes relief. Parents also described feeling helpless, exhausted, upset, depressed, frustrated, trapped, incompetent, out of control, unable to function and totally overwhelmed. They explained their loss of objectivity, their need to block out the experience and their battle for their infant’s or toddler’s survival. Some parents described the experience as hell or total nightmare, and most blamed themselves or others. Many described crying, praying or shouting as emotional reactions to the stressful situations. Many described a loss of reality and automatic functioning.

Functioning like robots

The absolute shock of their infant’s or toddler’s diagnosis left some parents in a position where they could not function normally, make decisions, nor be fully responsible for their own actions. Sometimes this reaction was perceived as beneficial because it protected parents from the intense stress of the moment. One father described his situation this way:

D: I functioned like a robot, it wasn’t reality, and it really wasn’t until 3 or 4 months later that I gained some retrospective objectivity of the whole thing. I was in shock, I can tell you
(laugh) and I think the shocked state helped me to function, to at least learn the basics and get the job done. I can't remember how I did it ... it's like a haze, a mental block.

This father perceived his reaction as a protective mechanism to help him through the learning process, and to guide him through the trauma of his son's hospitalization. For other parents, this type of reaction left them feeling incompetent, inadequate and unable to identify their own needs or the needs of their child.

As one father explained:

D: We were both physically and mentally exhausted and overwhelmed. We must have behaved like very incompetent parents ... there was so much to learn, but we didn't even know what we needed to learn and we were so afraid we couldn't cope.

The mother in this family described it this way:

M: That's true, we were literally two incompetents. I was anyway. I was totally incompetent. All my reserves had been used up and I couldn't cope at all.

The father continued:

D: So we functioned like robots. After 10 days of sleeping on a cot in a hospital ward and waking every 3 to 4 hours to check your little one's blood sugar levels, you become so exhausted you just function like a zombie ... You don't really think ... it's like a haze ... you do panic if you see a high or a low blood sugar but you don't remember what to do. You want to learn so that you can go home but you have no confidence ... the stress blocks out your ability to think ... to make rational decisions ... you think you'll never be able to understand or recognize your own child's needs.

Most parents attributed their "robot like" behaviour to shock or sheer exhaustion. Whatever the parents attributed this behaviour to, they felt unable to take control at that time and relied heavily on health care professionals for support and guidance. In particular, these parents relied on the nurses who taught them how to handle their infant's or toddler's regimen. Although this behaviour could be identified as a coping strategy implemented by parents during this initial phase of their experience, it is also described as a reaction or response to perceived stressors for the purpose of this study.

Denial

"Denial" was another response or reaction linked to the above theme of "functioning like robots".

Parents described this as a defense or protective mechanism to help them through the initial trauma of their
child’s hospitalization. Parents explained that this response of thinking, "if I don’t know how to do it, I won’t have to do it" was a form of defense that eased them into the situation slowly. A mother explained:

M: I knew we needed to learn all these things but secretly I didn’t want to. Initially I thought if I don’t know how to handle this then it won’t need to be done ... we can just forget it ... I guess it was denial really ... a defense mechanism ... and maybe that was good because we still didn’t know what we were getting ourselves into ... not until we got home ... and maybe that’s just as well, in retrospect.

Although the complexity of their child’s needs led parents towards a response of denial, each parent concluded that there was no viable alternative; they were trapped and had to learn. The parents’ description of these feelings constitutes the next theme.

Feeling trapped

The realization that "there is no way out and we have to do this" was the parents’ perception of the situation that led to an emotional response that generally guided parents towards coping with the demands of managing their infant’s or toddler’s diabetic regimen. However, this realization was fraught with emotional resistance for as long as possible. Most parents described struggling with their emotions. They tried to listen to educators, but couldn’t hear, couldn’t comprehend, and resisted as long as possible. Eventually they realized there was no choice. One mother explained her initial emotional response this way:

M: There was so much to learn, so much to do ... I couldn’t comprehend it all to begin with ... people were talking, explaining ... but I couldn’t listen ... I didn’t hear what they said. All I was thinking was that I cannot handle this, I cannot cope ... ... Then I realized there was no choice ... I had to ... after all, this was my child.

Another mother explained:

M: Well, we really had to do it ... there was no choice ... our child’s life depended on us.

Despite realizing there was no choice, one mother still described her feelings of disbelief at the enormity of what she was expected to do for her child.
M: My initial reaction was one of disbelief. All this testing, injecting, meal planning ... as well as caring for all the other needs of our baby ... I was overwhelmed. ... But we knew she had to have it [insulin] and we knew we had to do it or she'd get sick or die ... so there no alternative really ... I HAD TO DO IT.

This important perception of having no alternative, or no choice in the matter of learning the complex diabetic management regimen, could be considered a coping strategy employed by parents to manage their current stressful situation. However, because it is inextricably tied to the parents’ emotional responses and feelings of being trapped, it is presented as part of this articulated experience.

Many parents also explained the guilt and pain associated with learning the required regimen. When describing her difficulties with managing her young son’s diabetes at home, one mother referred back to her hospital experience this way:

M: But it brings back all the guilt and the pain. You see, when we were in the hospital and the nurse was trying to teach us, I wanted to say "Go away, I’m not ready to do this, I can’t do this, I won’t do this." I wanted it all to go away, but as the days went by I realized I had no choice, I had to do it. This was my child, he needed this to stay healthy so I’d better listen, I’d better be able to do it or else.

A father said:

D: We had no choice ... but we felt trapped. We wanted a choice ... but it wasn’t there.

Parents wanted a choice, but there was no way out. This realization left parents feeling vulnerable, trapped and wanting to escape from the entire situation. One mother explained:

M: Initially I felt some control. That was very brief because seconds later they were putting I.V.’s into her and she then had to stay in the hospital for a week. I just felt like someone had shackled me ... all these people were telling me I had to do these things and I just felt really scared and I wanted to go home. My initial desire was to escape ... I wanted to go home but I knew I couldn’t. I had to stay with ‘G’ and then the first night at Children’s Hospital was hideous because I kept on visualizing all the things I’d have to do for ‘G’ for the rest of my life!

Initial feelings of wanting to escape, wanting to go home and wanting to avoid all the people who were telling them what to do were shared by all parents in the study who described their hospital experience. Often multiple stressors experienced by the parents evoked feelings states that resulted in anger and blaming.
Parents' Perceptions of Caring for Infant Diabetes

Blaming

Once parents got over the initial shock of their child's diagnosis, they often became angry and began questioning why such a thing could have happened to them. In searching for a cause, most parents initially blamed themselves or someone else, and coming to terms, or accepting their child's condition, was sometimes made more difficult by grandparents who were struggling with the same thing.

Physical and emotional exhaustion were described by parents as stressors that evoked friction and anger and led them into the emotion-laden state of blaming.

Blaming each other or blaming themselves appeared to result from the parents' anxiety and stress related to events occurring during the young child's hospitalization. One mother who had just finished describing her experience of spending a night in the I.C.U. with her 19-month-old daughter explained her reactions:

M: When ‘C’ [dad] came back the next morning I just laid into him ... poor thing, everyone must have thought what a terrible woman I was ... my poor husband who felt so terrible as well, I just laid into him, blaming him and it wasn't his fault. I think he felt worse than me. It really strained our relationship.

R: It must have been a very difficult time for you both ...

M: Yes! Then ‘G’ got a little better and went to the cardiac ward — not the diabetic ward but the cardiac ward! ... and within 24 hours she was up and walking around, a different child ... the I.V.'s were gone. I had my little girl back ... and we were in a room with all these other little children with tubes everywhere, and surgery and I felt so ashamed because I’d been out of control ... but it was the stress of course ... I haven’t blamed myself since ... I know I mustn’t ... I didn’t know and I was under all this stress, but I blamed myself then.

Another mother described her difficulty with resolving self-blaming that was initiated in the hospital setting, but then was sustained throughout each phase of her experience.

M: Our relationship was so strained. ... You see, we come from Italian families, and this was our only son. The grandparents didn’t believe such a little child could get diabetes ... they wanted to know why. I know they blamed me because I had gestational diabetes ... they blamed ‘S’ [dad] and me ... and I think ‘S’ blamed me. He doesn’t blame me anymore (14 months post-diagnosis), I know that ... but I think he did at the hospital, and I will never forget that feeling ...
Of course, the doctors and nurses told us it was no-one's fault ... but then they couldn't fully explain how 'C' got his diabetes either ... so I still blame myself, the feeling's always there ... I think it always will be.

One father explained how depressed and down he got in the hospital.

D: You get so down and blame each other. It was very bad in the hospital, you know, we were so angry. I think the nurses must have thought we were terrible, incompetent parents ... You see, we blamed them. We blamed the doctors. We blamed the lab techs. Sometimes we even blamed our little boy when he cried.

These parents not only blamed themselves and each other, but they blamed hospital staff, especially those who performed painful procedures on their child. Other parents also blamed medical staff, particularly when it was difficult to make a diagnosis in a six-month-old infant.

The family whose infant was admitted to a small community hospital at the time of diagnosis described their reactions this way:

M: I blamed the doctors. I thought they were a bunch of incompetents. One said he thought it was meningitis, another said it's gastroenteritis ... then they phoned Children's Hospital and came back and said it could be diabetes. I didn't know who to blame.

D: He could have died, but then they sent him to Children's.

Blaming often resulted from the parents' feelings of guilt or anger over their own actions, and these feeling states will be presented in the next theme.

Guilt and anger

Although guilt and anger are two distinct and different feeling states, parents often intermingled and interrelated the two when relating their stories. Guilt often evoked feelings of anger, and anger often resulted in parents feeling guilty. Consequently, both responses will be described together. Many parents felt guilty about their treatment of irritable toddlers prior to the diagnosis. Many described how angry they had been with a whiny, clinging child and how badly they felt when they realized how ill their child was.

One mother vividly described how angry she had been with her toddler before the diagnosis was made, and how guilty she felt following the diagnosis.
M: So one day I got very, very angry with her because she was so whiny and so clinging and so bad! I threw her into her crib ... I almost hit her, can you believe that, I almost hit my little girl, and I am a fairly calm and rational person generally ... so I could see how another Mom ... say a single mom or someone without support, might be tempted to hit their child ... I called ‘C’ [dad] and told him I’d almost hit ‘G’, it does strain the relationship, you know ... and I went outside in the garden and chopped and chopped at the tree. That tree still reminds me of how upset I got, but I hit the tree, not little ‘G’ ...

R: Yes, I understand.

M: And next week, she was limp and lifeless in the hospital ... and she must have been feeling so ill the day I threw her in her crib. I feel so guilty.

This mother also described how easy it was to become angry with a toddler who was displaying the symptoms of hyperglycemia, and how driven to despair and frustration a parent could be. This mother had realized there was something wrong with her toddler, but ignored the symptoms for some time. She had difficulty coming to terms with the fact that her daughter was ill.

M: Oh yes ... and afterward it’s the guilt. When you are in the hospital with all the other things to contend with, it’s so difficult to get rid of the guilt. What did we do to this little kid, she was so ill and yet we got so angry with her, you never get over that guilt.

R: So you felt very badly that you had ignored ‘G’s symptoms and that you had lost patience with her, even though you didn’t know she had diabetes at the time?

M: Well, you see, I couldn’t believe we didn’t notice, didn’t clue into the symptoms. I kept telling the nurses in the hospital I nearly hit her. Do you know I nearly hit my child? And I thought if I kept telling other people, it would make it all better, be a catharsis for me, cleanse me of my guilt. I really felt I was a terrible, neglectful mother, and yet this little kid had been so whiny, so unreasonable, so miserable.

R: Did talking to people about your feelings help?

M: Um ... I think by the time we got out of the hospital, maybe even in the hospital, I began to accept it and people at the hospital were absolutely wonderful.

This parent had attempted to ease her guilt by talking it out with the nurses at the hospital. Like other parents she was having difficulty coming to terms with her actions, and saw herself as a neglectful mother who needed reassurance from health care professionals in order to dispel the intensity of her emotions.
Guilt was also described in terms of parents blaming themselves for their infant's or toddler's diabetes. A mother who had a traumatic pregnancy and delivery with her young son, who later developed diabetes, explained her feelings of guilt this way:

M: Well I felt guilty and responsible for 'R's diabetes, I wondered if it was the trauma when I was pregnant. I also felt this tremendous burden of responsibility. I felt I had to do everything in the beginning, before I became so depressed I felt I had to do everything. After all, I was the mother, this was my child, I'd given birth to him.

... You see, he's our only child, he's very special and I feel so guilty, as if I've ruined his life and maybe could have prevented this.

Later in the interview, this particular mother referred to her feelings of guilt again:

M: Unfortunately, I still feel it's my fault. I think maybe it was environmental, something I did, something I ate, and because no-one really knows the cause, I guess deep down I will always think it's my fault, even though no-one has said so. Maybe one day some research will establish the exact cause, and then I'll know it wasn't me.

R: And what about you, 'H' [dad], how do you feel?

D: I didn't blame 'M' [mom], never did and never will, because my brother's child has diabetes too and it could be that connection, but no one is to blame.

Because of the complex etiology of diabetes, it is difficult to convince parents that they are not responsible for the onset of their child's illness. The guilt, the blaming, the fears and frustrations were described by parents as recurring on a continuum through all phases of their experience. However, the overriding and pervasive need to take their child home provided parents with the impetus and strength to struggle with their emotions and carry on.

These accounts of the parents' experience have explained and described multiple emotion-laden reactions and responses to events surrounding their infant's or toddler's diagnosis and hospitalization. Parents described feelings such as shock, anger, fear, disbelief, devastation, helplessness, exhaustion, being out of control or totally overwhelmed by their situation. These feelings were evoked by multiple stressors experienced by the families during their child's hospitalization. Some coping strategies employed by
parents to handle their stressful situation were intertwined and described simultaneously with the parents’ emotion-laden responses.

**Coping Strategies Employed by Parents to Manage the Situation**

Coping behaviours identified by parents in their accounts were both positive and negative and either contributed to or detracted from the parents’ level of adaptation. Because of the initial acuity of the young child’s condition at the time of diagnosis, followed by a rapid stabilization period and apparent return to normal health and activity for the child within the hospital, parents described a variety of reactions and responses. Coping strategies such as being assertive, learning to manage the young child’s condition, seeking support, understanding and describing the child’s condition, looking for a cause and clinging to hope were utilized by parents to deal with the child’s hospitalization, and also in anticipation of taking the child home. The ultimate goal of parents was to provide adequate care for their infant or toddler with diabetes at home.

**Being assertive**

One of the major emotional responses described by parents was their feeling of being out of control and totally overwhelmed by the hospital experience. Trying to be assertive was a coping behaviour used in an attempt to restore some control over their situation.

During the early hospital experience one of the fathers explained his assertiveness this way:

D: We started putting our foot down, saying no more lancets, no more blood tests. I think they thought we were very bad, we wanted to do it ourselves. We were very adamant in the end. It was our son, our little boy. We were in this strange clinical environment and all our little boy had was us to lean on for love, support and guidance. He was only two and it was a very trying time for us. I’m sure the hospital staff were very tired of us and our demands.

The child’s stress over blood sugar testing called for intervention on the parents’ part. The parents’ level of stress was related to their child’s situation. Consequently, by reducing the amount of stress for their child, these parents also reduced some of their own stress and frustration. The parents took into account
the clinical environment, the benefits of their intervention for their son, and the level of control they had a right to assert as parents. In being assertive the parents also took on some of the responsibility for their child's care.

In another situation, the need to be assertive was related to the mother's total exhaustion through lack of sleep and constantly feeding her baby. Finally, the mother told hospital staff that she couldn't cope anymore. As a consequence, action was taken to reduce the toddler's feeds and insulin, and both infant and mother slept much better. The mother explained her actions this way:

M: You see there was all this stress, incredible stress. We used to feed him all night. We were trying to force feed him every three hours because they said he might go low. We were up all night doing blood tests and feeding. I was afraid to go to sleep in case we missed a feed. Then one night I said, "No more, I can't take it." I was in tears of frustration. The doctors and nurses said okay and we reduced the insulin and he slept and I slept better, and he didn't go low that night...I felt so relieved.

Another mother who admitted to having to take full responsibility for her young son's care because her husband couldn't cope described her response:

M: The main problem was the needles, because he was so small he didn't understand at all. It was such a struggle. He'd procrastinate ... think of every reason under the sun not to have it and that was very difficult. Also, his dad had a hard time. He'd procrastinate too, saying, "Why don't you just leave the injection today." ... Then it was the two of them against me. The nurses were very sweet. There was a special little room and we used to go in there. I used to say it has to be done ... I knew it had to be done so we just go on with it and it was over. But I had to be very assertive and just get on with it.

In this second situation, the mother's assertiveness was directed towards the father of the child. Both the child and father procrastinated over insulin injections, which undermined the mother's position. In this case, nurses were supportive of the mother's assertiveness and this provided her with the confidence in her own abilities when it was time to take the toddler home. She explained the benefits of her actions this way:

M: It helped when we got home because even then it was two against one, both procrastinating, saying "Don't do it today. Let's leave it," and me just getting on with it ... no nonsense. Two-year-olds are very accepting though, and very forgiving, which makes that part easier.
Another mother explained how being assertive about food for her child helped initially, but not entirely:

M: Even before the diabetes we had a fussy eater. Then in the hospital they told us what he had to eat and I knew he wouldn’t eat it. My thought was how can this be? Is this how life is going to be, is this what we’ve come to? I can’t cope. I’ve got to get out of here, it’s too much for me ... Then I decided; I’m his mother ... I know he can’t eat all this so I told them ... I told the dietitian and we gave him cereal and milk ... but I didn’t understand enough then ... not about nutrition anyway ... We didn’t really understand our little boy’s needs.

For this family, the assertiveness was necessitated because of the toddler’s prior eating behaviours. Only the mother understood the nuances of her young son’s fussy eating pattern. She realized that the expectations of hospital staff were impossible for her child to meet, and saw the need to intervene. At the time of her assertiveness on behalf of her son, this parent was unaware of her child’s total nutritional needs. However, her knowledge base improved as she learned how to manage her toddler’s dietary regimen in the hospital setting.

In order to take their infant or toddler with diabetes home, all parents were required to obtain a basic level of competence in handling the day-to-day regimen. Consequently the parents’ accounts described the learning process leading to this competency.

**Learning to manage the young child’s condition**

Because the parents’ ability to manage their infant or toddler’s diabetic regimen at home depended on what they learned in the hospital setting, this learning experience impacted dramatically on the parents’ total perception of caring for a child with diabetes. Major issues and concerns surrounding the daily management will be discussed in phases two and three of the parents’ experience. However, the initial learning experience and its implications were described quite dramatically by parents. One mother explained about her problems with needles:

M: Even before we went to the hospital with ‘G’ I had this phobia about needles ... and my fear of needles was accentuated in the hospital when I heard I had to give them to my own little girl ... Also, I didn’t know how I’d ever manage the inflexible regimen they taught us ... I’m pretty organized generally, but to be so inflexible with a 19-month-old seemed near to impossible ... it filled me with panic. But then I thought this is my child, she really needs my
help now so I’d better learn how to do it for her sake. I read all the books and asked so many questions.

This mother’s ability to overcome her fear of needles and to learn was initiated by her feeling of responsibility toward her daughter. Asking questions and reading books about diabetes were coping strategies employed by this mother, as well as by other families in the study.

It appeared from the data that the parents’ perception of the teaching, learning situation also impacted significantly on their ability to learn. Some parents explained that the technical approach to teaching, and the specific and precise instructions given filled them with panic. They described feelings of resentment toward health care professionals because they were not treated as responsible parents able to rationalize and make decisions. Ironically, these parents had previously described themselves as feeling incompetent, unable to make decisions and functioning like robots. These contradictory statements within accounts were fairly common to most parents. However, comparing the need for rigidity as opposed to flexibility for a young child’s future lifestyle was a matter of concern to most parents.

Parents who felt they were given no leeway or flexibility had more difficulty coping. The following account from the parents of a two-year-old illustrates how stress affected their ability to cope, and how a different approach by health care professionals might have helped them cope better. The father began the description this way:

D: Well, I think our experience in the hospital might be significant. I know we were stressed, but we are also fairly intelligent. We were taught things so technically, so exactly, like you’ve got to do it this way, there is no leeway, and because of this we became panic-stricken and felt we must do it this way and could never deviate. I think if someone had told us there was just a bit of flexibility it might have been easier.

M: I think I would have felt better if I had been treated as ‘R’s parent, as a responsible human being with some ability to rationalize and make decisions. But I didn’t feel that way at the time. It was as if I were being told, you must do this and you must do it this way. Then you go home and the full responsibility for the child is yours, day in, day out, but no one understands that. They cannot imagine what it’s really like and how it affects you.

R: So you really felt that you were given no leeway at all?
D: Not at that time. Now it could have been our inability to understand or our limitations at the time in light of our levels of stress.

R: And do you think if you had been told all about the flexibility that it would have helped and eased your stress?

M: Well, in retrospect, I realize now why they are so precise and so specific because these at least are specific guidelines to follow.

D: However, I would have felt more comfortable and less afraid, I think, if I had been treated as an equal, or at least had some leeway explained to me. You see, we were so busy learning technical things to do with the day-to-day management that we had little time to deal with our emotions, and no one really warned us about the emotional impact. They were more concerned about the logistics of blood tests, insulin and meals and snacks on time. To be honest, I didn't understand the emotional impact either ... I was like a robot ... kind of dead inside, going through the motions, and it wasn't until 5 or 6 months later that I realized the terrible impact this had on us ... so maybe it would be a good idea to set up an interview for parents after the child's diagnosis just to ask them how they are feeling emotionally ... not how are the blood sugars, or how is the diet, but how are you, how are you managing emotionally?

M: You see, parents themselves don't know how they feel. They are too caught up in the daily management, trying to get everything done. They have no time to feel!

R: I understand.

D: You know, if we'd had someone like you come to talk to us then, just sit and listen and let us talk, it would be so therapeutic ... you've no idea how therapeutic it is just to sit here today and talk.

These parents explained that what they really needed was someone to understand their emotional needs, someone who included them in the decision-making process, and someone who would listen to them instead of telling them what to do. However, these parents also admitted that due to all the stress of learning how to manage their child's condition, parents themselves lost perspective, and did not always have the ability to make rational decisions. The parents' inability to comprehend any room for flexibility in their child's daily regimen also heightened their confusion and increased their stress.

Although these parents were describing their learning experience, they also identified a need that was expressed over and over again by all parents in this study. The need for empathy, understanding and
someone to listen to their story was described by parents as a source of reducing stress and was referred to throughout all three phases of their experience.

For other parents the learning experience in the hospital was quite different. These parents perceived the acquisition of simple, factual knowledge as a means of reducing their stress and providing them with the confidence and ability to manage their young child’s regimen at home. They preferred the technical and specific approach to teaching. This approach met their learning needs, and the fact that much of the decision-making was taken out of the learning process for them was perceived as beneficial. These parents described an ability to remember exactly what they had been taught when they received the information in a precise and simple manner. One mother explained what a novice she was and how secure she felt when told exactly and precisely what to do. She viewed health care professionals as supportive and found the teaching, learning situation beneficial. She described the experience as follows:

M: Once we started learning it was like a miracle. It gave you a wonderful sense of security because you were told exactly and precisely how to do everything. People at the hospital were wonderful and so supportive ... we were such novices, such greenhorns but they went over things again and again ... almost like we were children, not adults at all ... but everything was so new we needed that.

We learned everything together ‘C’ [dad] and I and ‘G’ s grandparents. We came out with a very good attitude, and I think before we left the hospital we felt pretty comfortable with the whole thing ... The training they provided was excellent and when you got home just remembering exactly and precisely what you had been taught made it simple and invaluable. The decision-making was taken out of it for us and lessened the stress.

Different approaches and attitudes toward the teaching, learning situation, and different expectations of health care providers and educators, contributed to varying perceptions of the hospital based learning experience for parents in the study. Levels of stress experienced during the initial teaching experience were also reflected in the parents’ accounts which described their ability to manage their child’s complex regimen at home.

For some parents, learning was enhanced by their prior knowledge of the situation. For others, lack of prior knowledge was an impediment to learning.
Parents' Perceptions of Caring for Infant Diabetes

One mother described differences of approach to the learning between herself and her husband:

M: Well ‘A’ [dad] is a dentist. He was used to injections and medical terminology and he understood and learned more quickly than me. Nothing seemed to bother him ... but it really bothered me ... so we were at different levels ...

In this family, the mother’s stress was increased because the father’s medical background allowed him to understand and cope better. The mother was at a different level of comprehension and ability. She went on to explain that, in particular, the injections and need for blood glucose monitoring on a 15-month-old bothered her, and she felt inadequate because of her husband’s competence. Some of this frustration and feelings of inadequacy continued at home, and the mother perceived her husband as accepting their young daughter’s condition much more philosophically than she could. The difference in levels of comprehension and ability led to differences in opinions about the child’s daily management at home.

For other parents, learning together was an important aspect in the process of coping. Including fathers in the education sessions eased the mother’s apprehension, and contributed to continuation of shared responsibilities once the young child with diabetes was discharged from hospital. A father explained:

D: They insisted that fathers took time from work and participated in the teaching sessions. This was so helpful. It felt good to be included, and of course I began to realize how important it was for us both to know all these things in order to help ‘D’. I quickly understood that ‘Sh’ [mom] couldn’t handle all this alone ... that it would take two of us working together to manage all the injections and "pokes" and other responsibilities ... and because the nurses stressed this sharing of responsibility, it really stuck in my mind and I remembered it.

M: I couldn’t have coped alone. I needed ‘A’ [dad] beside me. It took one to hold and one to inject with the insulin ... also we both needed to know about handling the blood sugars and the food ... so we sat together, did everything together, and tried to help each other understand.

The realization that both parents would be needed to ensure the continued management of the child at home resulted in adjustments being contemplated and planned even in the hospital. A mother explained:

M: When we sat together in the teaching sessions and ‘C’ [dad] was so calm and accepting, it calmed me. I thought, ‘It can’t be so bad ... we are in this together, so I won’t have to do it all alone. ‘C’ [dad] will help.’
The mother of a young infant described her experience this way:

M: I knew it was too much for me to handle. ‘T’ [dad] was there with me, helping and supporting ... yet I felt so lonely, so devastated. I thought ‘T’ will never be able to go back to work ... I can’t cope alone. Then ‘T’ arranged to work just part-time until we got this all together, until I could cope better. You see, our baby was so young I thought I might go into postpartum depression with all this to do, and no support. So, when I knew ‘T’ would be home part of the time, I felt better.

The need for help and support in handling the regimen for such a young child with diabetes was recognized by most parents, and adjustments to lifestyle were initiated in the hospital setting.

Some of the variability in approach to the learning situation appeared to be related to the presence of multiple stressors in the parents’ lives, prior knowledge of diabetes or other health care problems, and the parents’ perceptions of the support systems available.

Seeking support

While in the hospital, most parents described looking to nurses, doctors or other health care professionals for support. They also looked to each other. Some parents described their experience of becoming too reliant on health care professionals and experiencing panic at the thought of going home and managing alone. One mother explained:

M: The nurses were so supportive. I almost became too reliant on them, thinking I’d never manage without them at home. But there was a counsellor who assured me I’d manage, and it gave me confidence. ‘C’ [dad] was so good. He was feeling so awful, worse than me, but he appeared calm. I leaned on him a lot. I honestly don’t know how a single mother could manage. It takes two of you to do everything, one to hold and one to poke ...

Counselling helped parents to cope with the fears of going home and managing alone. However, the need for parents to support each other was paramount. One mother who received little or no support from her husband relied heavily on her own mother. She explained the advantages of having a mother who was a diabetic herself, and could understand the situation.

M: I couldn’t have got through this without my mom. She was supporting me, then taking care of ‘G’ [dad], who was experiencing acute anxiety. With two other diabetic grandchildren, my mom was quite a pro.
Most parents looked to their extended families for help, but did not always receive the anticipated support. Grandparents were reported as being equally stressed and as afraid as the parents. They were unable to comprehend the situation, or deal with the complex needs of their diabetic grandchild. Parents were often too busy, or stressed, or preoccupied to spend time with extended family and explain the situation to them. Consequently, the extended family became upset and were not very supportive. Most parents described their child’s diagnosis and hospitalization as being one of the loneliest and most stressful times in their lives. Many did not obtain the support from those on whom they had relied in the past and, instead, turned to other parents who had young children with diabetes and who could understand the situation. Most parents explained that, unless you have experienced a similar situation, there is no way you can possibly understand. The following accounts explain the parents’ perceptions of seeking support and the problems they encountered.

M: Well, everyone came to visit, then left us. They were too afraid and I think we were too stressed and too busy to explain things properly to them. They were very upset.

The parents of the five-week-old infant described their experience.

D: Our family was not very supportive. They didn’t understand. They hadn’t gone through it. They were afraid. They didn’t want the responsibility ... they were even afraid to visit ... it caused a lot of heartache.

M: Later, this other mom who was still breastfeeding her diabetic infant came in to visit. She was the only one who understood, because she had been through it. She became my major support. Later, we kept in touch by phone.

One family had just moved from another city and explained their experience.

D: Well, we’d just moved here into a new neighbourhood, then ‘D’ got sick. All our family were in other cities. We’ve never felt so lonely, and so in need of support.

Another family described a similar lack of support.

M: Well, diabetes happens so suddenly, and our family doesn’t live here, so it was a devastatingly lonely time for us. I’ve often thought that had another parent with a small child with diabetes come to visit us, we would have felt much better ... someone who could listen as well as share their experiences ... You need support, but you need someone who understands, not a sympathetic grandma who says “don’t hurt him,” because you know you have to hurt him. And someone who doesn’t understand just adds to your grief and your guilt.
Support from people who understood, and not from people who would be too sympathetic toward the child was stressed. Too much sympathy was perceived as counter supportive, and many parents in the study offered to provide this empathetic support for other families.

In general, parents looked to each other as major support systems at this time of crisis. However, although parents described their need to support each other, many acknowledged difficulty doing this.

D: We knew we had to support each other, but it wasn’t easy. We had breakdowns in communication, misunderstandings. We saw in each other all those combinations of inflicting pain and restrictions on our child. It was easier to blame each other than to support ... But in the end, we got it together, and then we tried to explain our son’s condition to our family.

Conflicts and misunderstandings over their child’s condition and management also contributed to breakdowns in communication and the parents’ difficulties in supporting each other. Parents perceived an ability to explain their child’s condition to others as being an effective way of gaining support.

**Understanding and describing the child’s condition**

A need identified by parents was their ability to understand and to describe their child’s condition to others. Parents perceived the necessity to explain diabetes to friends and relatives in order for them to understand and to provide support. One father drew a verbal analogy to explain his understanding of diabetes and how he would try to explain it to others.

D: I knew I had to understand diabetes for myself. Then I tried to think about how I could explain diabetes to other people ...

R: (silent pause as the father gathered his thoughts)

D: I’d like to explain to you how I feel about this, and an analogy I try to draw for myself so I can understand. You see, I look on diabetes as a wood burning fire and heating the house with a wood stove. Instead of having a draft on it, that’s open all the time ... the open draft is the insulin working all the time, and the logs you put on are the food, so you have to feed that fire all day long to keep it going. You might put on two big logs in the morning (that’s breakfast), then two smaller ones for snack, two big ones for lunch, and so on. You can never leave that fire when the draft is open, you have to keep on feeding it day in and day out, or the fire dwindles and goes out. So, I explain ‘R’s diabetes to friends like this to try to help them understand, and you know, I had to find a space in my head to monitor all this and to understand how to keep this fire going. It was difficult to push all this other stuff aside in my head because it was pretty much full, but I have done.
The father used a great deal of energy in order to equate his son's diabetes with a familiar domestic situation that could be easily understood by others. However, he explained that in his attempt to do this, he had blocked out many of his previous thoughts, and had become excessively preoccupied with his son's diabetes.

In another situation, the mother of an infant diagnosed at 5 weeks of age explained that it was impossible to describe her son's condition to others because she didn't even understand what was happening herself. She explained:

D: We really blocked the whole thing out. You see, 'T' was our first baby, and we couldn't even understand the normal things a baby should do ... so to try to explain what to do for a baby with diabetes was overwhelming. We tried to explain to other people but it was tough ... so confusing.

Another mother who tried to explain the required treatment regimen explained how difficult it was in the beginning, due to her own confusion.

M: Even trying to explain to others ... like my sister ... it was very hard. She didn't even want to learn ... she was so afraid ... so in the end I didn't try ... I found it confusing myself anyway ... even I didn't fully understand.

Because of the multifaceted nature of diabetes and the diabetic regimen, parents found it difficult to describe their child's condition to others. They also found it was difficult for others to accept. As one mother explained:

M: Well, you see, no-one in our family could understand or accept it. We didn't know anyone who had diabetes. My mother said, "he's much too young, diabetes is only for old people, he'll grow out of it, just you see." And I wanted to believe my mother, I didn't want to believe the doctors, I wanted the doctors to be wrong. After all, we couldn't explain it. We didn't know the cause.

Parents also had difficulty because there was no one specific cause for their child's diabetes.

**Looking for a cause**

Trying to establish a cause for the diabetes was a pursuit undertaken by some parents, even though it had been explained to them by health care personnel that there was no known or no specific cause. This pursuit for a cause was a coping behaviour used by some parents in an attempt to resolve guilt and
blaming, and to reduce stress. In one family the father’s preoccupation in looking for a cause was perceived by the mother as a method of absolving himself from responsibility. The mother explained:

M: Well, ‘G’ [dad] just read and read. Being a librarian, he was sure he would find the cause. Maybe it was because we were both older parents. ‘G’ was 50 and I was 43 when ‘A’ was born. Maybe it was the food we fed our son, because both ‘A’ and his dad loved sweet and rich food. All ‘G’s energy went into looking for a cause, instead of helping me to take care of ‘A’ ...

However, this mother also accepted the possibility that genetics played a large part in her son developing diabetes. Because of a strong family history of diabetes, this mother almost expected it.

M: Of course, despite what they told me about viruses and immune systems, I knew part of it was genetic. I’d almost expected it with my brother’s two children being diabetic and my mother too.

In another family, where the father could trace no family history of diabetes, finding a cause was important to his peace of mind. He explained:

D: Well, we have absolutely no diabetes at all in our family ... none. And of course, ‘K’s [mother’s] father has diabetes ... So I was tempted to say, yes, that’s the cause. But the doctors say there is no one cause. It would have been easier for me to have a definite reason why this happened. I think I could have accepted it better.

For another family, the parents’ own personal philosophy about life helped them to accept their child’s condition without fully understanding the reason why. The mother philosophically explained her views this way.

M: Well, if we are looking for a cause, I expect we are both to blame. You see, ‘S’ inherited the diabetes gene from his dad, but he inherited the protein deficiency gene from me, and maybe either or both could kill him. But we gave him life, he’s our son. He’s very close to his dad ... There is a definite and special bond between them. Maybe because ‘B’s [dad’s] brother also has diabetes, and ‘B’ ... well, he feels very close to them both.

As for me, or as for us, who needs to know the cause. He’s a great little guy. Sure, he has diabetes ... and that’s a hassle ... we have to watch him carefully ... but hey ... we could all be blown up tomorrow ... anything could happen, so why worry about something you can’t change ... We just accept it, even if we don’t fully understand why.

All parents did not share this philosophy. Many had difficulty understanding and accepting their child’s condition. As one mother explained:
Parents’ Perceptions of Caring for Infant Diabetes

M: You see, there is no diabetes in our family. I tried to trace it back, but couldn’t, then I thought it must have been me. I’d given it to him because of my gestational diabetes. I went all over town asking every doctor, "Did I give this to my son?" I was sure it was me, but the doctors said not, it wasn’t me, it was nothing to do with gestational diabetes. But that didn’t stop everyone saying, "it’s her, she gave it to him." Even in the hospital, when they began to tell us all about this, the shots, that it was a lifelong illness, I just cried and cried every day. I thought, "Oh God! This poor little boy, all his life, he can’t eat, he can’t play sports, his whole life is ruined" and I couldn’t think straight in the beginning.

Most families did look toward a family history of diabetes as the cause, even though it had been explained to them that there was no one specific cause but, instead, a combination of factors that contributed to diabetes in children. This searching helped to reduce some of the guilt and sadness experienced by the parents.

Considering alternatives

Another strategy used to reduce these guilt feelings of despair was to consider their child’s diabetes against alternatives. Although shocked and taken aback by the diagnosis of diabetes in their young child, many parents used the coping strategy of comparing their child’s condition with alternatives. This comparison involved considering diabetes relative to other chronic conditions, and most parents described diabetes as a favourable alternative. One mother who had been told her child might have leukemia was even relieved at the diagnosis. She explained:

M: I was terrified ... imagining the worst ... she looked so ill and pale.

Then they said she had diabetes. I WAS SO RELIEVED, CAN YOU BELIEVE THAT, I WAS ALMOST HAPPY ... I KNEW I COULD HANDLE DIABETES ... I thought I can handle that as long as my baby isn’t going to die ... can you believe, I was relieved. I thought of all the other things it could have been ...

Other parents compared their toddler’s diabetes to different conditions they encountered in other young children at the hospital.

M: Initially ... the whole impact hadn’t hit ... instead we thought of the other things it could have been ... like other horrible diseases and we preferred this to the alternatives.

D: Yes, it’s so hard to deal with. But one thing, when we were in the hospital we saw so many other kids with most terrible things, we were even feeling so lucky that it was only diabetes for ‘D’ and we could at least deal with that. You see, before the diabetes, we had never even
thought about the Children's Hospital or what went on there. Until something like this touches your life, you are totally ignorant of all the suffering and the children with cancer ... you just shut it out. I think parents of healthy kids should all go the Children's Hospital and just see all the pain and suffering that goes on there, it's a real eye-opener!

This downward comparison of diabetes was based on the parents' perceptions of other children with chronic long-term illnesses. During their own child's hospitalization the parents were exposed to multiple health problems that they had never encountered before. Consequently, their own child's diabetes was perceived as being less onerous. Another parent drew a similar comparison, but this time to more specific diseases.

M: On the ward with 'G' there were all these children with chest tubes and needing heart surgery and things like that ... and there were children with cystic fibrosis. I don't think I could thump my child's chest 4 or 5 times daily like parents of children with cystic fibrosis ... and I know 'G' isn't going to die, she's going to live and that makes a big difference to me. I can handle this.

However, this mother also explained how difficult it was to see her child pricked and wondered how she would handle it.

M: Of course, for 'G' there were all the I.V.'s and monitors, to begin with. Then people doing finger pokes 4 or 5 times a day. And sometimes I couldn't stand it. I just walked out and cried and prayed ... I wanted her to be cured when we went home. It was hard.

The father of a six-month-old infant who had initially been diagnosed with possible meningitis explained his ambivalent feelings this way:

D: When he was first diagnosed they said it could be meningitis. Then, when they told us it was diabetes, I was relieved ... I thought diabetes was better than meningitis. But I'm not so sure now. You see, he'd be over meningitis by now ... but diabetes, it never goes away.

This father had grown up with a brother who developed diabetes at 13 years of age. Consequently, he was aware of the many long-term implications of the disease. However, the mother interjected at this point, explaining:

M: Oh! sure, but he could also be brain damaged or dead, had it been meningitis. He's certainly not brain damaged .... and he's very much alive.
During their infant’s or toddler’s hospitalization, parents tended to compare diabetes with other acute or chronic conditions. Later, during phase three of their experience, a comparison was drawn between the young child and older children with diabetes. As well as comparing their child’s condition against others, parents also compared the modern management of diabetes with the treatment of the disease in the past. They considered all the advances in technology and management that would ensure a healthy future for their child. This looking to the future is described by the parents as an important strategy utilized frequently in their day-to-day experience.

Clinging to hope

During their child’s hospitalization, most parents had received education and information about developments in diabetic research. They expressed an almost false optimism for an early cure, and used this optimism and hope as a coping strategy and a motivating factor to struggle on. One mother summed up most of the parents’ articulated feelings this way:

M: You see, in the hospital they told us all about the research, and I believe they must be this close [mum put her hands close together] to a cure. Without that hope, what have we got? We believe there will be a cure for ‘G’ before she is a teenager. How I look at it, 100 years ago she would have died, 25 years ago there were no glucometers .. so they are whittling away at this ... what we have to do is to keep her well until the cure comes. That’s the least we can do.

After a pause, this mother continued:

M: At the hospital, they gave us faith and hope. That’s what we needed; it’s what kept us going and sustained us.

A father agreed:

D: We were given a lot of hope that a cure would be found. And with him being so small, we know that even if it isn’t a total cure, there will be new things to make it easier for him as he gets older. Our job is to prevent complications while he’s small so that when a cure comes along he will be ready. We went home with a lot of hope and determination to keep him well until a cure was found.
This hope for the future was a motivating factor that enabled parents to get on with the job of caring for their young child’s needs in the hospital setting. It also provided the parents with determination and confidence when they faced the stress of taking their child home.

Summary

Because most infants and toddlers are extremely ill when first diagnosed with diabetes, the experience of the diagnosis and hospitalization of their child was described as extremely stressful for all parents in this study. In their accounts the parents described multiple stressors, their reactions and emotional responses to these stressors and coping strategies used to deal with the stressful situation.

The initial stressor described by the parents was the diagnosis of diabetes in their child, and for most parents this was a devastating and frightening experience. The child’s emergency admission to hospital, time spent in intensive care units, the constant need for invasive procedures, and the alien hospital environment were all events or sources of stress contributing to feelings of shock, loneliness, disbelief, fear, helplessness, exhaustion and loss of control over their situation for parents. On top of this the magnitude of the task of learning how to care for their young child and manage the diabetic regimen was described by parents as overwhelming. Lack of understanding of their child’s condition, lack of privacy and the perceived loss of family supports for some parents exacerbated their level of stress. For other parents their past experience with diabetes influenced their ability to accept their child’s condition and adapt to the situation.

Despite the magnitude of this stressful situation, the parents also identified coping strategies utilized to deal with their child’s condition and hospitalization. Their accounts also outlined strategies used to accept and acquire management skills required to care for their infant or toddler at home.
Phase Two: Caring for the Young Child at Home

This phase of the parents' experience spanned a period of from six to seven months post diagnosis for most families, but some parents described it as lasting even longer. During this time period, the parents assumed full responsibility for the day-to-day care of their diabetic child. They struggled to achieve an appropriate standard of competence that would ensure the provision of safe, effective care and management for their infant or toddler, and they began to understand the widespread implications and the pervasive influence that diabetes could have on the child and on each member of the family.

Some of the variables that impacted on the parents' experience were the age of the infant or toddler at diagnosis, the presence of other siblings in the family, and the length of time since diagnosis. Some families were still struggling with this phase of their experience when first interviewed. Others had to recall the events that comprised this experience. However, regardless of the timeframe, issues and concerns arising from their efforts to manage their diabetic child's condition at home were consistent across all parents' accounts.

Perceived Stressors

Many of the stressors identified by the parents involved their struggles with events happening in their lives over which they had little control. The major themes extracted from the parents' accounts described the stress associated with taking the child home, necessary changes in lifestyle, perceived losses, the uncertainty and unpredictability of blood sugar levels, hyperglycemia and hypoglycemia, confrontations over food, giving injections, taking blood tests, and developmental issues for the child. When describing the stress associated with the impact of their young child's diabetes on their lives, the parents identified this stress in terms of issues and concerns that impacted on their situation. Most parents began their description with the coming home experience.
Taking the infant or toddler home

Going home was described as a frightening experience by most families. Although the child was now well and active, the magnitude of the task of caring for their child without the support of hospital staff was overwhelming to most parents. Being totally responsible for their child's management and very existence was perceived by parents as an awesome and frightening task. The fear of hypoglycemia was already perceived as a major stressor in the parents' lives. They were unable to relax or even sleep at night due to fretting and worrying in case their infant's or toddler's blood sugar levels fell low. Parents were apprehensive about taking their child home and described this as being a frightening new phase in their lives. A phase when they were in charge but not necessarily in control, and a phase they had looked forward to with confidence initially, but which proved to be a nightmare experience. Parents did not feel ready for this responsibility. One father described the event quite graphically:

D: After 10 days, we were ready to go home. At least they said we were ready. We didn't feel ready. But by this time, 'R' was lively, putting on weight, and we knew we had to take on the responsibility and go.

M: Yes, and we came home and I was saying to myself, "I don't want to do this, I don't know what to do, I cannot do it." I remember I couldn't sleep, I was terrified he'd go low in the night. I was up testing his blood sugar 3 or 4 times a night, I was so anxious. Then he started going low all the time because he was beginning to honeymoon, and he was on so much insulin, almost 9 units, and he hasn't even got back up to that dose again yet. We didn't know about changing the insulin then, so we spent all day, every day, trying to feed him. It was a nightmare, and I did a blood test and he was 4 and he wouldn't eat and we didn't know what to do.

Another family described it this way:

M: We had just wanted to get out of there and back home into our own beds to relax, to sleep. We were excited and felt confident. But the impact of the total responsibility for our son's life and very existence suddenly hit me. Instead of sleeping, we were up all night fretting and worrying in case his blood sugar went low. At the hospital they said we didn't need to do a blood test at night, but we did for reassurance.

Another mother described the event of leaving hospital and beginning to care for their child at home as moving on to a new experience.
M: It was like leaving all the security and support behind. A new phase to our lives. We were in charge now. 'C' was our responsibility. But we also knew there was no going back to how life was before 'C's diagnosis. Almost everything would be different.

As well as the stress associated with taking the child home, parents also described their realization that life would never be quite the same as it was before. Everything would be different. Struggles with the stress of necessary changes in lifestyle was the next theme identified from the parents accounts.

Changes in lifestyle

The initial impact of their child's diabetes was described in the context of immediate changes required in lifestyle, due to the imposed management regimen. The stress associated with changes in lifestyle revolved to a great extent around the imposed management regimen. Trying to fit all the necessary injections, blood tests and dietary requirements into their day consumed parents' thoughts and their time. Some parents' work schedules had to be changed in order to accommodate the giving of insulin or the testing of blood. Fathers were required to give up social pursuits in order to be home to handle certain aspects of their child's required care. The imposed and rigid regimen led the parents to frustration and exhaustion, and fears that they would never handle this situation. The parents' lives revolved around their child's need and the parents saw no way out. The very specific instructions provided for parents in the hospital created anxiety because of their inflexibility. Most parents believed implicitly that they could not deviate in any way from the imposed schedule without causing extreme harm to their child. Parents perceived no room for flexibility and the schedule became the backbone to their very existence. The impact of the required regimen on their lives was perceived differently by individual families, but the outcome remained constant. A major change in lifestyle was required. The following extracts from the parents' accounts illustrate the extent of this stressor. One mother explained:

M: When we came home from hospital it was so hard, so incredibly hard. I used to look at him and say, "This can't be happening to us, no way."

For one thing, 'S's [dad's] and my relationship changed. Our life changed.
‘S’ [dad] was so good, so patient, but he had to change his shift. You see, he still does all the needles and finger pokes. The hospital experience was too traumatic for me. So now ‘S’ works from 11 p.m. to 7 a.m. graveyard, so he is home all day.

I’ve braced myself and can do needles if I have to, but ‘S’ is much better. So I do all the food, ‘S’ does all the needles.

It was hard for us to believe we had to do all this for our little boy.

Another family described the impact of the teaching and instructions provided while their child was hospitalized.

D: I think initially I was so concerned about the specific instructions we were given in the hospital, and how we could manage that inflexible regimen, which seemed virtually impossible in a two-year-old. It was set out as extremely important. I was so anxious and worried when we first came home.

The mother agreed.

M: Now, in the beginning, when we came home I said, "How can I manage this child?, I can’t do it, how can I change my whole life to revolve around this imposed schedule?" ... and having a two-year-old who doesn’t know what’s going on, and doesn’t understand needles, and doesn’t want to eat, I thought I just can’t do this, I cannot, it was just frustrating.

Many parents described the difficulty they had with deviating from any aspect of the learned regimen. One father put it this way.

D: Difficult? ...

It was to us. You see, we heard all this "you must do this, and you must do that" and this schedule became the backbone to our very existence. There was no flexibility in our world, we couldn’t see a way out and every detail had to be followed.

Another mother explained:

M: In the beginning, we didn’t change a thing. I became convinced that sugar was poison ... I didn’t dare deviate in any way at all.

It was Halloween, just after he was diagnosed, and he was so little, he was happy just opening the door. But you know, he just sat there on the stairs and he had to hold this chocolate bar in his little hand and he wouldn’t let go. It was quite pathetic, but I had to say "No, you can’t eat" and he said "I just hold it". It began to melt but he just held on to that until he fell asleep, just as if he had to be a part of it, and I felt so bad. But I couldn’t even let him have a taste.

This strict regimen also created an issue surrounding food for another family.
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M: It took us a while to get used to this, you see, he can’t even have an off day, we seem to be eating and feeding him all the time. Sometimes we just seem to sit at the table all day, and if he’s had his insulin dose, I know he’s got to eat. Then at other times, he’s hungry but it’s not mealtime.

One mother explained how the imposed restrictions had changed their life by taking some fun out of events for both herself and her young diabetic child. She described how even the simple pleasures of preparing meals or cooking together had to be changed because of dietary restrictions for the child. The resulting stress caused reactions of anger and despair for this mother.

M: Before ‘D’ had diabetes, it used to be fun. He’d help me bake or, when I was cooking, he could taste or have a carrot stick or as many cookies as he liked. Now we can’t do that, it’s all stopped. All those spontaneous things we used to do, we can’t do them anymore. This schedule has taken so much fun out of life, but I’m afraid to change anything ... it could do ‘D’ harm.

A father explained how his life had changed because of his feeling of responsibility to his wife and young son. Night school classes were dropped because diabetes consumed his every moment and his every thought.

D: I was enrolled in French. I love the language, but then ‘R’ developed diabetes and my whole life was in turmoil. My head was so full of ‘R’s needs and what he had to do all day and every day that there was no room left for French. I gave it up. I gave everything up. The stress even at work was unbelievable ... I would imagine what was happening and I wanted to be there ... at home with ‘R’ [child with diabetes] ... not at work.

Another father explained.

D: I was so stressed out I developed stomach pains. I think it’s an ulcer. You see my work is so stressful ... so demanding ... usually it occupied my thoughts, then I’d come home, relax and play with my kids. Now that’s all changed. When I come home we don’t play anymore, ... it’s blood tests or insulin or worrying about blood sugar levels. I never relax.

For most parents the pleasure of playing with their children after work had been exchanged for blood tests, injections and worries about blood sugar levels. In general, some of this total absorption with their child’s diabetes and total inflexibility on the part of the parents did ease before the end of the phase of their experience. However, the imposed changes in lifestyle remained and had to be dealt with. One parent explained it this way.
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M: In the beginning the stress was so great we couldn’t relax at all or even think about ourselves. We were riveted to what had been taught in the hospital. There was no leeway, no deviating, no ability to be flexible or to make any decisions. We thought this was how life would always be ... this was our new life .. the only way to handle our child.

The parents’ perceived need to implicitly and vigilantly follow the imposed management regimen resulted in losses that the parents at this point saw as irretrievable. These losses comprise the next theme.

Perceived losses

All the families in the study described losses in their lives due to many changes imposed by their child’s diabetic management regimen. These losses were perceived as extremely stressful and disruptive, and induced periods of mourning. The parents described losses of spontaneity, flexibility, freedom, support systems and other intangible losses. No family could see a way to overcome these losses. The loss of flexibility was perceived as inherent in the rigidity of the child’s management regimen. Loss of spontaneity was perceived in the need to always plan, always prepare and be constantly vigilant in thinking, feeling and anticipating for the child. Loss of freedom was described as feeling trapped and always tied to the child and the regimen. It included a fear to leave the child with others. Loss of support systems resulted in social isolation. Intangible losses were difficult to describe, but parents attributed these losses to themselves and to their child.

When describing loss of flexibility the parents stressed their need to follow the same routine day in day out, with deviation. They perceived any attempt at flexibility as leading to a crisis situation in the form of low blood sugar levels for their child. One mother explained.

M: There is no flexibility. It must be the same food at the same time every day. There is no more sleeping in on weekends. Insulin is due at 7 a.m. Everything must go like clockwork. At 11 a.m. whatever we are doing we have to stop. It’s blood test time, then lunch. If you try to be too flexible the blood sugar drops and ‘C’ is in a crisis situation. Every nap time I have to waken him right at 2 p.m. ... poor thing can’t even have a full nap.

Because of the loss of flexibility little time is left between meals and testing for spontaneous outings or the decision to do something different. Everything had to be planned. Loss of spontaneity was attributed to the demands of the daily management regimen. One family explained.
M: I had no idea how demanding this diabetes would be. In these six months since ‘D’ developed it I’ve noticed we haven’t been as spontaneous as a family anymore.

D: We can’t just go out and let the kids run and when they are tuckered out, bundle them back into the car like we did before or like other families do. We can’t do that anymore, everything must be planned, what food to take, how active he is or when the next meal or blood test is.

M: That’s true, it’s affected us as a family. But also little ‘D’ can’t be spontaneous anymore. We’ve just been going through a phase when he can’t or won’t eat, he’s had a cold and flu and doesn’t want to eat. But unfortunately he has to eat and I feel so sad.

I feel I’m not feeding ‘D’ anymore, I’d feeding the insulin and I’d give anything to just let him be a normal little boy and not have to eat if he isn’t hungry.

Another father described loss of spontaneity at the frustration of taking his toddler to the park, but having to stop in the middle of a game and think about the child’s next meal or snack. He compared his restrictions to the freedom of other families, and mourned the loss of both freedom and spontaneity. He explained the changes since his son’s diagnosis.

D: I find it’s like hell. I used to enjoy going to the park. Now I feel a lack of freedom, a total loss of being ourselves ... I have to think about the next meal ... the next snack ... or if we’ve been running too much, I have to wonder if ‘S’ is too low ... yet he’s been doing what a normal little guy should do. Sometimes we have to rush home ... we can’t stay there like the other kids, and it’s so frustrating. You’re always afraid.

Loss of freedom was interrelated with loss of spontaneity. Parents described feelings of being trapped or tied like a prisoner to their child with diabetes. The demands of the management regimen also resulted in the loss of freedom of choice. Parents no longer had the option or choice with regard to the foods their child could eat. They also had no choice as far as insulin was concerned; they could not omit or delay it even for a day. One mom explained:

M: It’s like being trapped ... you can never get away, never be free again. Like a prisoner, only the prison is diabetes; and the chains are insulin, or blood tests.

Another mother explained:

M: For the first few months after ‘T’ was diagnosed, I didn’t go anywhere. By the time I got him fed and dressed and in the stroller, it was feed time again or time for another blood test. So I’d stay put, but I didn’t just lose my freedom, I lost my friends, too. I was afraid to visit and afraid to leave my baby.
Being trapped and a fear to go out, or to leave their child with others, created a situation that led to loss of support systems for families. Parents were often so tied up and busy caring for their child's needs they and no time for friends or for socializing. One mother described her situation:

M: I was utterly lonely, but I had no time for anyone else. I was consumed by my baby's diabetes.

Other parents described situations where they became so busy and so wrapped up in their child's needs that they didn't take time to teach others how to care for their infant, and they didn't attempt to go out. Fear on the part of relatives and friends to get involved also contributed to the loss of support systems. They saw how all-consuming the child's regimen was and they felt they couldn't handle it. Parents themselves were often too exhausted to socialize. As one mother explained,

M: It's too difficult to describe really, but I was so busy that other people were afraid to call ... my family were afraid to visit, I had so much to do ... so I wouldn't see a soul all day until 'T' [dad] got home ... then I was too exhausted to socialize ... I'd go to bed while 'T' took over.

Sometimes parents would make the effort to get a babysitter in or attend a family function. However, the child's management regimen posed a stumbling block, and others were not willing to cope, or care for the child.

M: The babysitter said she would come, then changed her mind. She was afraid of all that had to be done.

Another mother explained:

M: Even my sister won't do a blood test, don't ask me why. She'll care for 'J' for short periods only, but won't cope with tests ... I can see it's a big responsibility.

A father explained:

D: We are really still afraid to go out. You see, even relatives are afraid to be left.

M: Yes, and even though it's lonely as hell, I feel safer when I'm there ... it's stressful not to go out ... but it's more stressful to leave him.
One mother who wanted to obtain support and return to work on a part-time basis found it impossible to get the support she required. As this mother explained, other people did not consider a toddler with diabetes to be a normal child.

M: I wanted to return to my job, just two days a week. We interviewed sitters; one was afraid of liability ... one told an acquaintance (not us) that she preferred to care for a normal child. It really hurt. You see, we try to look at 'S' as a normal little girl, but it made us realize that she's not.

Only one mother was truly philosophical about the loss of support systems, and she described her feelings this way:

M: Well, after all, he is only very young and on top of that he has diabetes ... you see, I figure that mothers of new babies don't trust other people with their infant much, anyway. When you have a child so young, you usually do most of the care ... so diabetes or not, I probably wouldn't have got out as much anyway, and I wouldn't have felt comfortable leaving him for long either ... not until he's older, anyway.

Generally, socialization was a problem for parents during the early months of their experience, and loneliness was a major source of stress. From the parents' accounts, it appeared that the younger the diabetic child, the greater the amount of loneliness experienced. The parents of a young infant explained:

M: I feel so isolated, so cut off, so utterly alone sometimes. You can't find a babysitter because no one will care for a baby with a health problem.

D: Once I go to work, all M [mom] has are the four walls to stare at. It's very lonely for her.

Parents of older toddlers did take their children to the park, to play groups and to grandparents' homes. Nonetheless, all families experienced changes in socialization patterns. A father explained:

D: Well, we do go out, but we usually take 'Ch' with us. It's different now ... we never get time just for ourselves [parents], and something is lost ... we've lost a spark, an energy, a joy we had before.

Like this father, other parents also described intangible losses for themselves or for their child. These losses were difficult to explain, difficult to truly identify, but something was gone from their lives. Sometimes the loss was described as the loss of a normal child, the loss of opportunities for the parents,
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or the loss of opportunities for the child. Sometimes the parents wistfully mourned the loss of happiness or loss of the joy of life. The following parents' accounts describe these losses.

M: It's so difficult to describe, to define ... you see, she'll never have the opportunity to try things ... the new foods and tastes a 15-month-old should experience. She was just beginning to get excited about food ... now she will never have the pleasure.

Another mother tried to explain:

M: It's like a part of you and your life has gone forever .. it's difficult to explain, but we were just beginning to really enjoy being parents, planning or dreaming of 'R' as a hockey star ... it was ... a feeling of lost opportunities for him.

Parents of an infant described it this way:

D: Well, he was so tiny, and something inside of him had gone so very wrong ... it didn't seem fair ... we felt sorry because we'd never know what it could have been like had he been normal.

M: It's as if I've lost something, some part of me has gone forever.

Yet another mother explained:

M: She lost something a toddler should have, but I can't describe what ... a bit of her spark has gone, I think ... a bit of her joy of life.

The father of a two-year-old summed it up this way:

D: It seems to me 'D's lost so much for such a little child. It's his freedom, his independence ... all that's gone. His life is ruled by tests and needles ... even his moods seem ruled by his blood sugar levels ... he can lose control so quickly, and that's not his fault. I feel sad he's lost so much.

All the losses identified by parents were related in some way to the child's diabetic management. This imposed regimen was intended to minimize or control fluctuations in the young child's blood sugar levels. However, blood sugar levels in these infants or toddlers could become a major source of stress to most parents.

Unpredictable blood sugar levels

The unpredictable nature of diabetes in this young age group was a major factor contributing to the stress experienced by parents participating in the study. Parents described the pervading and
overriding stress of unpredictable blood sugar levels as contributing to intense emotional responses of fear and frustration. Fear of low blood sugar levels and hypoglycemia led to changes in attitude, an inability to trust others and loss of support systems. Fear of complications due to high blood sugar levels contributed to depression and psychosomatic reactions in some parents. Rapid fluctuations in blood sugar levels caused stress and concern for all families.

The stress associated with constantly changing blood sugar levels in the young child were not limited to the parents' early experience of managing the diabetes. Instead, this dichotomy between the fear and frustration of both hyperglycemia and hypoglycemia resulted in sustained ambivalence and confusion through both phase two and phase three of the parents' experience. Consequently, although the major description of the parents' struggles with these stressors will be presented here, it should be noted that this theme must be considered on a continuum through both this and the long-term phase of the parents' experience. The recurring or sustained stress arose from the parents' perceived struggle to both recognize and prevent the acute and frightening onset of hypoglycemia, while at the same time being cognizant of the need to prevent long-term complications associated with hyperglycemia. Dealing with the toddler’s or infant’s mood swings and irritability associated with rapidly swinging blood sugar levels was a constant source of stress. Controlling their own emotions was another struggle identified by parents. Accepting and attempting to understand rapidly fluctuating blood sugar levels was an ongoing struggle. The following parents' accounts illustrated the pervasive nature of this stress.

D: You see, there is lots of stress and concern, particularly if his blood sugars are too high or too low and to be able to stay in control of your own feelings is the hardest part, because he isn’t always in control of his feelings, and to be able to show love and understanding all the time to an infant who is out of control because of high or low blood sugars ... that’s the hardest part ... as a parent, to control our emotions.

M: I need to hold back on my emotions and feelings. These up and down blood sugars ... it drains the emotions, and causes constant stress. It’s a constant battle.

D: Yes ... we know his mood swings are due to high or low blood sugars and it isn’t fair to discipline .. that’s when he needs all our love and patience.
M: But sometimes I run out of patience, and I get very, very tired with all these constant mood swings.

The parents then tried to explain the complexity of determining the cause or causes of their young child's mood swings. Not knowing the cause was another source of stress for parents.

D: Well, we have to think about so many things, has he had enough sleep, is he tired, did he eat enough, did he eat too much, is it snack time?

M: But his own feelings, just whether he is deciding to be a little beggar or whether he's high or just excited. But he is often totally uncontrollable. When he’s very low, he’s very irritable. But when he’s high, he’s also very irritable, so it’s difficult for us to know if he’s high or low. He’s so little, he can’t explain and we are not experts enough to pick up on it.

The mother of a two-year-old explained her frustrations this way:

M: Oh! dear, the blood sugars. I get so frustrated. It's impossible to predict those blood sugar readings and they swing all over the place.

During the first few months following diagnosis, some children enter a honeymoon or remission phase of their diabetes. The beta cells of the pancreas begin to pick up and produce insulin again. This endogenous insulin, coupled with the insulin by injection, can contribute to low blood sugar readings, and is a confusing concept for parents to grasp. For the mother of a two-year-old who had previous experience with diabetes in her own father, this honeymoon phase was a major source of stress. It was difficult to understand that an adult's diabetes is considerably more easy to stabilize than is a toddler’s. In this case, the past experience with diabetes was not helpful in providing information to ease the parents' stress.

M: When we first came home, he went into the honeymoon phase and kept going low, and I kept thinking it isn’t working for ‘D’, the insulin isn’t right for him and we’ll never get him under control. You see, with my dad, he has this neat little package of testing, and insulin, and food, and exercise ... they all balance out. Whereas for ‘D’, there is no neat balance, he’s totally unpredictable, all over the place and his activity is so erratic.

For other parents, the utter frustration of being unable to control their infants' or toddlers' blood sugar levels led them to ask, "What have I done?" or "Why can’t I control this?" Even after days when the parents had conscientiously handled every aspect of their child’s care exactly as they had been taught,
the blood sugars fluctuated by extreme levels, which were difficult for parents to comprehend. One
mother described her frustration this way:

M: This is what’s so frustrating about diabetes ... the sugars go up and down, up and down and
sometimes for no reason. You see, we always try to do the same exercise, the same nap, and
one day the blood sugars are high, the next too low, and I can't get a handle on it. Even
when I seem to have done everything right, it makes no difference ... and the other night she
was 4 (mmol/L) at supper, then 20 (mmol/L) at bedtime and I get so frustrated, why does this
happen, what have I done?

The stress of seeing their toddler’s blood sugar level rise from 4 to 20 mmol/L in a matter of four hours
was apparent in the way parents articulated their story. For very young infants, the swings in blood sugar
levels could be even more dramatic. The parents of an infant who had been diagnosed at just six months
described a drop in blood sugar from 25 to 3 mmols/L in a matter of 30 minutes. This was described as
a frightening experience that created considerable stress for the parents.

D: Sometimes he’s very irritable and we think it’s the blood sugar. Mind you, he can be irritable
most of the time, so that’s not really a sign, so often we don’t know. His sugars can skyrocket
for no apparent reason, and he can suddenly go very quiet and be low for no apparent reason;
it’s very distressing.

R: Yes. I understand.

M: The blood sugar can drop from 25 to 3 mmol/L in a matter of half an hour. It’s very
confusing, and quite terrifying. You don’t know what to do to prevent it in such a young
child.

While health care professionals tended to caution parents against the dangers of consistently high
blood sugar readings, most parents identified an equal or more pervading fear of low blood sugar levels.

**Hyperglycemia and hypoglycemia**

The fear of consistent hyperglycemia and the threat of long-term complications for the child
caus ed panic and physical symptoms in some parents. The information provided by health care
professionals, which outlined the long-term effects of hyperglycemia, was interpreted by parents as the
means towards compromising their young child’s future. The stress of seeing even one high blood sugar
reading caused parents to visualize the many complications associated with diabetes for their child. Due
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to the stress of their child’s diagnosis, parents initially misinterpreted information provided by health care professionals, or else could not understand or comprehend everything that they were told. This lack of comprehension added to their stress. The parents of a two-year-old discussed their initial stress during the very early months following their child’s diagnosis.

M: Well yes, I was so worried about high blood sugars and long term complications for ‘R’. You see, with him developing diabetes so young, what are his chances for the future, I worry about all the secondary effects, all those complications.

D: Yes, and I’d like to add to that, because in the hospital they told us all about the dangers and long-term effects of high blood sugars, so when we came home, every time I saw a high reading of 20 (mmol/L) or more, I’d get this terrible knot in my stomach every time.

M: Yes, and I’m sure they did explain that to us about occasional high sugars, but we were too stressed to hear, or else we couldn’t understand, or couldn’t comprehend. It used to be "Oh! what can we do?, how can we deal with this, it’s high again!"

D: I will never, ever forget that terrible knot in my stomach ...

Past experience with diabetes in the family could also influence a parent’s perception of the situation. Parents who were already experiencing diabetic complications in an elderly relative were particularly concerned about the diagnosis of diabetes in their very young child. One mother experienced considerable stress when she could not control high blood sugars in her two-year-old.

M: I feel badly because I can’t control the blood sugar. You see, my father already has eyesight problems and circulatory problems, and ‘D’ is in this a lot longer than my dad. I always imagine the harm high and low blood sugars are doing to ‘D’ inside.

This concern was shared by other families, in particular by one father whose brother had been diagnosed at 12 years and was already suffering some long-term effects at only 28 years of age.

D: ‘S’ is so young, we’ll need to protect and care for him. I don’t want him to run into the problems my brother has ... not kidney problems.

Although concerned about consistently high blood sugar readings, some parents expressed less concern about the long-term future for their child. Instead, they were focusing their hopes on a cure for diabetes. One mother rationalized her lack of concern about long-term complications by explaining that she expected a cure for her daughter within 10 years.
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M: Oh yes! I'm concerned when you think about all the complications and side effects of diabetes and I try not to think about them now ... and we are worried when she comes in with the odd high blood sugar ... but we are hoping that there will be a cure in 10 years time and that we won't have to worry about that. So, we are not really trying to worry about that right now (laugh).

Many parents expressed less concerns about the future but, instead, described the intense and constant fear they had of hypoglycemia. Apprehension and anxiety about their inability to detect hypoglycemia in their child were major stressors described by all families in the study. Sometimes parents overlooked high blood sugar readings in order to avoid hypoglycemic episodes which they found extremely frightening. The following accounts expressed the parents' fears:

M: I am so afraid, so stressed out about low blood sugar reactions that I often let the blood sugars run high. I have to forget the future and live for today .. my goal is to avoid lows, avoid seizures ... it's the threat of a seizure that causes the stress.

The parents of an infant diagnosed at 5 weeks explained their fears this way:

D: It is absolutely terrifying for us ... the thought of him going low ... Because we are more worried about lows, we tend to keep his blood sugars a little higher. Not enough for him to have ketones or anything like that, but high enough so that 'K' [mom] isn't constantly concerned about seizures or severe reactions. If he's low, that is constantly a very high stress level for us.

M: Yes, you see our stress level is very high if he is low. Even during the day, he can just suddenly drop ... if his blood sugar drops, it's crisis time ... he becomes unmanageable .. I can't feed him ... and I'm usually alone when it happens, and I think he might die right then and there. So I really worry about lows more than highs.

D: We keep his blood sugars in a higher range than we should, but it's the only way to manage our stress.

Keeping the blood sugar high was a coping strategy used by these parents to manage stress. However, other coping behaviours employed by parents to prevent and manage hypoglycemia will be discussed under the third conceptual category of this phase of the experience. Parents went to great lengths to avoid hypoglycemia in their children, and these coping behaviours reduced stress. However, to further illustrate the fear and panic experienced by parents with regard to this stressor, the following parents' accounts are provided.
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M: One day I remember I went out shopping and it was time for his insulin so ‘H’ [dad] did a blood test and it was 3 something, but he went ahead and gave all the insulin anyway because it was just before supper and he thought ‘R’ would eat. Then ‘R’ refused to eat and ‘H’ was totally paralysed with fear and panic.

D: Yes, and that is when we had no idea what to do except to feed him like we’d been taught. It was a 24 hour nightmare, up all night feeding little bits of juice or honey.

The mother went on to explain their actions.

M: You see ... we remember being told maybe only 10 minutes without food and a low blood sugar could result in a coma and we hung on to that. We saw no room for leeway and so were extremely anxious.

Some parents in the study had been forced to hospitalize their children due to severe hypoglycemic reactions. Consequently this recurring, sustained or absolute fear was of paramount importance to most parents because they perceived it as keeping them aware and alert. Because their young child was too young to understand or to give parents any indication of impending hypoglycemia, the parents themselves felt totally responsible for their child’s safety and well being. Fear of hypoglycaemia also led parents to feel extreme stress if their child would not eat.

Confrontations over food

A major stress identified by parents was the experience of getting their young child to eat. Parents described the need to feed the insulin, or feed this monster called diabetes rather than feeding the child. The need to prevent hypoglycemia through feeding the child became a major issue for parents that led to confrontations with the child. Parents described total feelings of panic if their child wouldn’t eat, and many acknowledged the practice of force feeding the child in an attempt to prevent hypoglycemia. Most parents perceived insulin as a powerful substance not to be handled lightly, and the effects were perceived as being extremely dangerous if the child wouldn’t eat. The constant emphasis on food contributed to behaviour problems in the child, and feelings of inadequacy and frustration in parents. One parent explained.

M: I have a constant fear that she won’t eat for me. The fear begins before I prepare the meal ... and builds up until I see the whole meal gone ... I know it’s stupid, but I’m so afraid she’ll
Other parents explained their initial reaction to feeding their young son in the early weeks following his discharge from hospital. This self-imposed regimen was a major stressor to parents.

D: Well now, most days in the beginning we would start with breakfast and that would take 1½ hours. He’d be down from his high chair about ½ hour then it would be snack, then lunch, then snack, then supper, then snack. Almost his whole day was in the high chair, it was a joke, but we thought it was how it would always be, morning to night ...

M: My thought was how can this be ... is life always going to be like this? We didn’t know there was an alternative.

Having a fussy eater only heightened the parents’ anxiety, and parents explained that they had been frustrated by this prior to their child’s diagnosis but that now the stress had been increased significantly.

D: Because we started with a fussy eater, this diet perpetuates that. We are continually pushing food into him, anxious that he gets the allotted amount of milk or protein, and what substitute can we make to ensure his proper intake? This is an ongoing concern for us.

Vomiting was also a major source of stress for these families. Parents explained the need to refeed their child immediately after the vomiting stopped, because of the fear of blood sugars dropping.

They expressed the sentiment that “food ruled their lives”.

M: Food is a major issue ... if he vomits we have to rush and feed him all over again ... just as soon as he’s stopped vomiting ... poor little tyke, I feel so sorry for him ... he can never have peace; even if he doesn’t want to eat, he has to.

One mother explained how sad and totally helpless she felt when her two-year-old just threw up his hands one day and said “I’ve had it”.

M: I was making him eat and suddenly his little hands went up in front of his face and he said “I’ve had it” ... and I wished he could have had it ... I wish I could let him go like other toddlers, but with diabetes you can’t have “had it” ... you have to eat.

Another mother asked.

M: How do you tell a 15-month-old she has to drink all the milk?
Confrontations over food could also occur if the child was hungry but couldn't eat because it wasn't meal time or snack time. Some parents described their toddler having major temper tantrums if not allowed to eat. Some children requested more food after a meal, and parents felt mean having to say no.

M: I felt cruel and mean. He was so little, so hungry. It was as if he'd been starved. He craved food. He'd steal food off other peoples’ plates and stuff it in his mouth and swallow so quick you couldn’t get it out ... even with his own meals and snacks he’d stuff it in so fast as if he were afraid we’d take it away. He’d say mine! mine! ... one day he stuffed 16 grapes into his little mouth all at once, I thought he would choke.

D: Yes, and often he would cry for more food and we’d give him pickles and cucumbers ... but how many cucumbers can a little one eat?

For some of the children and parents food was not a major problem. The parents still experienced anxiety in case the child wouldn’t eat. However, these toddlers had good appetites and ate well. For these parents the stress was reduced. One mother said.

M: I am so lucky. ‘G’ eats really well. She’s never been a problem with food and, since she is so young, she just eats what I give her. My main stress or worry is that things can change. I know that could happen and this concerns me ... However, currently food isn’t a problem, but injections are.

It appeared from the accounts that, if parents had less concern over one part of the management regimen, they had more concern over another. For parents who had no confrontations over food with their toddlers, a major stressor was usually insulin.

Giving injections

Because of a paranoia or often intense fear of needles, the idea of giving injections to such small children constituted a stressful procedure for all parents. Even one of the mothers who was a registered nurse, and gave injections to herself on a daily basis for a medical problem, acknowledged the stress involved with injecting her infant. Most of the fears and concerns experienced while the child was hospitalized carried into this phase of the experience, and giving injections was perceived as a stressful
daily event. Coping strategies employed by parents to manage this procedure will be discussed later. However, the stress of this procedure cannot be underestimated. As one parent explained.

M: It’s the stress ... I still cry ... I still get so frustrated and so depressed over the injections ... I feel cruel ... as if I’m violating my child because she cries so much. Whatever I do she struggles and cries. I feel so mean.

Parents described their own responses of crying, getting angry, frustrated and depressed. They were devastated by the need to physically hurt their child on a daily basis. One mother explained her horror when she saw bruising or bleeding at the injection site.

M: Her little leg is such a mess. You see she struggles then we get a bruise ... but it always takes two of us to do this .. one to hold ... one to inject. Sometimes we get angry with each other and tell each other "you are doing it all wrong" ... it’s just the stress but we shout at each other to vent our anger ... we forget that neither of us would purposely hurt our child.

The mother of one family in the study and the father in another family did not give injections or do blood tests on their child. The mother described her absolute fear of needles and her preference to leave this to her husband. This mother did admit that she could give the injection if absolutely necessary, but it caused major stress for her. In the other family the mother reported that her husband was totally unable to inflict pain on his son. Consequently, the injections remained her sole responsibility. All parents who did give the injections described problems with their infant or toddler crying, struggling and needing to be restrained. The extreme young age of the child made it impossible for parents to explain the necessity of the procedure to them. This only made the parents’ task more stressful and onerous.

One mother described a time when the struggle between herself and her toddler became so intense that she considered calling in the public health nurse. She explained.

M: I could feel the tension rising every day. I used to think why me, poor me, I can’t do it anymore. We have to take a break and call a nurse in. But then I thought of that as defeat ... what would my little daughter think if I couldn’t do this thing that was saving her life ... I’d give anything not to have to do it, but I wouldn’t let my daughter down.

In general, the problems with injections continued into the third phase of the parents’ experience and problems specific to that phase will be discussed later. Generally fathers viewed the task of giving
injections as less stressful than did the mothers, and mothers perceived the fathers’ techniques as being better than their own. Most mothers described delaying techniques or procrastination on the part of the toddlers. In younger infants it was no contest. Ultimately, as one father explained.

D: Well, when it comes right down to it we are bigger and stronger, and the poor little tyke can only scream in protest. We need to provide a lot of love once it’s over.

The stress of inflicting pain on their child was often overwhelming.

**Taking blood tests**

The other invasive procedure involving testing blood sugars caused less stress for all the families in the study. Each parent explained that pricking the finger and obtaining the blood was no big deal. The actual process of obtaining the blood was acceptable to most of the toddlers who often participated in the procedure.

All families took blood sugar tests faithfully four times daily, and some even took tests during the night when the child was sleeping. As one parent explained.

D: I’m totally amazed, after the first few days the blood tests were a snap. He’d hold out his finger and push the knobs on the monitor. He even puts the lancet into his finger sometimes ...

Another explained.

M: I do a blood test before I go to bed and ‘D’ doesn’t even stir or waken up ... sometimes he jumps and I know it must hurt, but he never cries.

Another mother explained.

M: I think it hurts me more than it does ‘S’. She runs to get the monitor for me. It’s part of her life.

The most stressful part of the monitoring procedure was obtaining the results. Most parents described a dread of seeing an exceptionally high or low reading. However, most acknowledged that these results were imperative to their peace of mind. Parents often used results to judge their child’s moods and behaviours. Because of the young age of the child at diagnosis, parents often had difficulty differentiating between normal toddler behaviour and diabetes-related behaviour.
Child's development

All the parents in the study described some knowledge deficit with regard to parenting skills and understanding the normal growth and development of their young child. Most felt totally overwhelmed by the need to care for a young child with a chronic illness and none had been prepared for the task. Only one family had an older sibling. In all other families in the study the child with diabetes was the oldest or only child. Parents found it stressful when they didn't know whether their child's behaviour was normal or induced by the diabetes. Consequently the child's development was a major concern to all parents. However, their perceptions of their child's abilities seemed to vary. This variability was often associated with the child's age at diagnosis. It was difficult for those parents whose infant had been diagnosed at only five weeks to recognize normal infant behaviour.

M: 'T' certainly was a very irritable baby but it's hard for me to know if that was normal. You see he was my first baby. It seemed he was just born then developed diabetes. I never knew what it was like to have a normal baby.

In contrast, parents of children diagnosed after the age of two could remember their child's development before diagnosis. Each described changes in their child's behaviour since they had been diagnosed. These changes included the toddler becoming more reserved, a little more timid, less adventurous and somewhat lagging in motor development. Parents rationalized this delay in development as being related to the pre-diagnosis months of lethargy, poor appetite, polyuria and polydipsia. They described this deterioration in their child's health as impacting significantly on psychomotor development, and perceived their toddlers as having difficulty catching up with developmental milestones in their peers. One mother explained her daughter's development this way.

M: Well, as a teacher I'm very interested in gross motor development as well as psychological and social development. I still feel 'G' is behind in gross motor development. She doesn't catch a ball yet, or attempt to kick a ball. She doesn't have the coordination of other two-year-olds that we know. She's not as active as some of the other toddlers in the park. I think it's because of the diabetes you know ... she was ill for over three months before it was diagnosed ... you know I think her cells were breaking down, then picking up again over a long period of time and it slowed her growth and development ... like when there wasn't
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enough insulin produced and she was irritable and tired, then she didn’t get enough energy to grow ...

Other parents explained their son’s lag in development this way:

D: I think he’s not entirely strong again yet, he seems a bit fragile and a little more susceptible to illness. He's not as aggressive or forward as some of the children his age, he stands back and I don’t know if we’ve encouraged it or whether the diabetes affects him.

M: He seems a bit insecure, he still hasn’t taken that step into being a real little boy yet. He sometimes still lets us feed him, he just sits there and lets us spoon the food into him like a baby and doesn’t try to take the spoon. Sometimes with other kids he just stands back and watches and I don’t remember him being like that before the diabetes.

R: So he seems a bit apprehensive?

D: Yes, well, you see, he isn’t pedalling his tricycle or anything yet like the other kids his age. He seems a bit delayed, and we think it could be all the emotional trauma of the diabetes and his being ill.

M: But it could also be our emotions, our fears, and us not letting him or not encouraging him to do things. You see, it has been emotionally draining for us too and I think I didn’t know what to expect of him or for him, and I have been very overprotective.

Conversely, the parents of infants diagnosed at only a few months perceived their children as being advanced for their age. Parents described these children as growing rapidly and achieving developmental milestones well ahead of their peers. They perceived them as being physically larger than other infants, being better coordinated and more cognitively aware. They described their infants as more aggressive than others their age. They attributed this in part to the amount of attention and encouragement their child received, and to the amount of time they as parents spent with their infant. One family explained:

M: He seems so normal, his eyesight is so good, he can see everything. Even a tiny little decal on a tiny car that we may have trouble seeing! And he’s chunky and tall ...

D: And he’s very smart, his development, his speech, his words are getting clearer and he is way ahead of his cousin who is 4 months older. He’s very smart, very bright, he’s certainly not retarded in any way.

M: He’s also very bossy, very aggressive and we’ll have to watch that. He’s certainly not backward in any way, but sometimes he’s too aggressive around other children; sometimes he even hits out at us [parents].
The parents of a second infant described their perceptions of their son’s development.

M: He’s a very bossy, assertive little guy, and this can cause problems around other children.

R: How does he compare with other little toddlers his age? What about his coordination?

M: Well, he is actually bigger and brighter and his speech is far advanced of others his age. My sister is a public health nurse and does assessments on preschool children all the time. She is quite amazed at ‘S’s vocabulary, says he’s as advanced as many children twice his age. I think she feels she has to assure us he isn’t retarded but we don’t need that, we just see him with his other peers. We know lots of toddlers all born within six weeks of each other and he is so far advanced, it’s amazing.

D: Yes, and at the park he can climb and swing like the 5-year-olds.

Although the latter two infants were still under two years, they had been diagnosed for a longer period of time than either of the two-year-olds described earlier. In general, families found it very important to compare their infant or toddler against other young children who did not have diabetes and, whether they perceived their child as developmentally delayed, or overly aggressive, the child’s development was a major issue for these parents.

Many parents remained unsure of their child’s development because they had no previous experience to compare with. The mother of a fifteen-month-old described it this way.

M: Well, ‘S’ is my first and only child. I’m a novice at being a parent. She was only 15 months at diagnosis and it seemed I had only just got used to being a mother and then, wham ... diabetes. I’ve no one to compare ‘S’ with, so when she kicks and screams, I’m not sure if it’s because she’s almost two, or whether it’s because something is wrong. It’s most frustrating.

A father concurred.

D: If only I knew whether it was the normal "terrible twos" or whether the tantrums were due to erratic blood sugars, I’d feel so much better. Just differentiating behaviour, or trying to determine behaviour is a major source of stress.

Other parents had problems with well-meaning relatives who wanted to make the child an invalid while the parents struggled to have their child reach normal developmental milestones. Grandparents who thought the toddler with diabetes should rest in order to get strong again were counterproductive in promoting growth and development for the child. One parent described her concerns this way:
M: Well, in the beginning, I thought ‘C’ wasn’t normal and I believed he would never be able to run and play like other toddlers again. Then I saw he could be perfectly normal and a healthy, happy little boy. However, my mother always wants to spoil him, to let him have his way because he’s not strong. She thinks if he rests he will get better. She doesn’t understand how much better the insulin works if ‘C’ is active. I worry because he loves to go to my Mom, but I don’t want his growth or development stunted.

In general, parents described developmental issues for their child as being matters of great concern. The parents’ inability to differentiate between normal and diabetes-induced behaviour was identified as a source of stress.

The foregoing accounts have described the perceived stressors of parents related to caring for their young child at home during the early months following diagnosis and hospitalization. Many of the stressors identified by the parents related to events and situations over which they perceived they had little control. They impinged upon the parents’ day-to-day experience and elicited major reactions and responses.

Reactions and Emotional Responses to Perceived Stressors

In this discussion of the parents’ accounts, emotional responses include the parents’ descriptions of feeling totally overwhelmed by the complexity of their child’s needs; changes in roles and relationships include the conflicts and friction parents experienced due to the multiple stressors.

Emotional responses

Emotion-laden responses described by parents were related to their child’s condition and the imposed complex management regimen. Although the initial shock of their child’s diagnosis and hospitalization was over, emotions such as anger, frustration, sadness, anxiety, worry and fear recurred frequently as each new struggle and crisis arose. Initial feelings of relief at the child’s diagnosis later developed into frustration as the impact of their child’s lifelong illness and the need for constant vigilance
and adherence to the management regimen was realized. Parents described an ongoing grieving process and sustained feelings of "why me", "why our child", "why us". One mother explained:

M: It's like an ongoing grieving process, this thing called diabetes never goes away ...

A father said:

D: We never stop being angry and sad, and sometimes the pain and hurt return again and again. With each new crisis we think "Oh! God, why us, why him?" He is so small, we wonder what he did to deserve this.

The persistent and intense fear of hypoglycemia was accentuated during this phase of the parents' experience, and worry over the unpredictable nature of their child's blood sugar levels evoked feelings of stress. One father dramatically explained:

D: It's an absolute riveting fear, it really never goes away, this fear of low blood sugars ... in such a small child, it's a constant source of worry.

A mother explained her feelings this way:

M: I'm an emotional wreck. If it isn't a fear of low blood sugar, it's the panic feeling over highs ... it's like a pendulum of emotions that constantly swing with the blood sugars.

Tensions between parents arose due to exhaustion, lack of understanding and the inability of parents to communicate. Some parents acknowledged that the worry of diabetes had taken over their lives, and they could no longer discuss or consider anything else. Differing values and expectations of parents led to blaming each other for their child's condition. Sometimes mothers became so engrossed in their child's management that fathers felt shut out or excluded. Many parents acknowledged feelings of depression and an inability to cope. They felt totally overwhelmed by the complexity of their child's needs, and consequently struggled with their emotions while attempting to handle their child's condition.

One family graphically described their emotional reactions:

M: You know, I went into a total depression and even 'H' [dad] couldn't understand how I felt. It was very frightening really, I actually had suicidal thoughts. One day I was driving across the bridge and 'R' was with me and suddenly I thought what is the point of all this, I can't go on and I had this desire to drive into the oncoming traffic in the other lane, to just end it all for 'R' and I. That's what I wanted to do, to end it all for both of us right then and there.
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D: (very concerned because he hadn't heard mom say this before) ... was it a recurring thought, 'M' [mom], or was it only a one time thing? I had no idea.

M: It was recurring, it came back several times, so I knew I needed help. The school board has a psychologist, so I was frightened and so I went for help; it was dangerous, I knew that!

D: (concerned) Well, you know at the time I didn't know, you wouldn't talk, 'M' [mom], you'd just sit. It was a like a big stone wall, a big silence ... you'd just sit, it was a deep silence I couldn't break; she was just gone!

R: So you couldn't talk together about it!

M: No, because all we ever talked about was diabetes and I couldn't do it anymore. I couldn't talk about diabetes; you see, all we both did was discuss blood tests and blood readings and insulin dose.

D: And we only discussed it at a practical, mechanical level, and it didn't increase our understanding at all.

R: So talking didn't solve it for you?

M: No, because there was something deeper going on, something very emotional.

D: Yes, and that emotional response cut us off from each other, I realize that now.

These parents went on to explain the mother's reaction to her child's condition and her assumption that she had to do everything for her son to compensate for his condition.

M: I felt so guilty, so responsible. I was older in my late 30's when 'R' was born. He meant so much to me; he was so precious. I became impulsive, thinking I had to do everything for him to make amends. I'd rush around and when 'H' [dad] came home, everything would be done. I became exhausted ... so tense ... I began to blame 'H', though he didn't understand how exhausted I was ... then something snapped inside. I couldn't talk anymore ... I shut him out.

Another family described their emotional responses and feelings this way:

M: We were both exhausted, yet totally unable to relax. When 'A' [dad] came home we would argue because we were both so tense ... there was this big emotional rift between us.

D: Yes, we couldn't communicate ... it was a buildup of anger and frustration we couldn't share ... we were emotionally drained.
For some parents it was painful, intrusive procedures that reduced them to despair and feelings of pity for their child. These parents described the experience of crying inside, cringing, or feeling physical pain and sadness when inflicting pain on the child. One mother explained:

M: It’s anger and pain for me each time I give an injection. I feel the pain ... you never get used to it.

Another mother said:

M: I cringe inside when I squeeze the blood from her tiny finger ... it’s a physical pain ... you see, I’ve tried it on myself, and I know it hurts.

For other parents, the demands of the total regimen left them feeling emotionally drained. These parents described feeling states of simply surviving and not really living. The mother of a young infant explained:

M: I had to breastfeed on demand, which was bad enough. Then the doctors wanted us to test his blood before each feed, day and night. He woke about every 2 hours ... we were exhausted ... I used to sit and cry as I nursed him. It wasn’t really living, it was a feeling of just surviving ... existing hour by hour. So engulfed in ‘T’ s needs, we were emotionally drained.

Sometimes feelings of pain and sadness were evoked when the young child was so accepting.

M: I often look at that little innocent face ... so trusting in me ... and my heart aches and my eyes fill with tears because I know I have to hurt him.

Another mother described her emotional responses during the early months as being difficult to control.

M: I think I was so fragile I’d just cry if someone even spoke to me, or asked me how ‘A’ was doing.

Because of the fragile state of the parents, conflicts and friction often arose due to changes in roles and relationships. These changes are discussed in the next theme as a reaction to the child’s condition.

**Changing roles, relationships, conflicts and friction**

Major changes in roles and relationships were described by parents in response to their infant’s or toddler’s diabetes. Although these reactions to their situation can also be considered as behaviours they were interwoven with descriptions of emotional crisis throughout the parents’ accounts. Consequently they
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will be presented here for the purpose of this study. Fathers’ socialization habits were changed due to the need for them to participate in their child’s regimen. Mothers delayed returning to work, or were forced by circumstances to stay home with their diabetic youngster. The child’s demanding regimen led to exhaustion and tension and the need for parents to seek respite and support. However, the roles of previously supportive grandparents also changed, due to their initial and overwhelming fear of handling the complex management. This led to changes in interaction patterns between grandparents and grandchildren. Some parents described a perceived change in bonding between themselves and their child. They associated this change with their need to inflict painful procedures, or to force-feed their child. Toddlers and infants sensed their parents’ tension and reacted to this tension. Relationships between parents became strained and conflicts and friction arose due to differing ways of perceiving and handling the child’s diabetes. One mother explained:

M: We fought all the time. Particularly over giving the shots. You see, ‘A’ [dad] handled it better than me ... he would tell me I’m hopeless and then take over ... then ‘S’ [toddler] would settle down ... I’d feel mortified and cry ... this diabetes drove us all apart.

Another mother explained:

M: We would fight over food. ‘S’ [dad] would say surely he can have a bite ... let’s give him a bit. He didn’t understand the food, and it would cause bitter confrontations. I was trying to be so strict, and ‘S’ thought I was just being difficult. I felt so defeated, I didn’t want ‘Ch’ [toddler] to get sick. I was afraid to feed ‘Ch’ the wrong things. ‘S’ [dad] thought a small amount wouldn’t hurt.

However, in one family that had been experiencing marital conflict prior to their child’s diagnosis, the mother described how her son’s diabetes acted as a catalyst for bringing the family back together again. Because the parents came to the joint conclusion that they had to work together to support their son, they were able to put aside their differences and help and support each other. The mother explained:

M: It had been an emotionally draining year before ‘A’ was diagnosed. You see, when ‘A’ was born, ‘G’ [dad] was working full time and I was home. ‘G’ [dad] was totally tied up in his work, it was as if he didn’t have an infant son at all. I used to get tired and crabby, home with a new baby all day and every evening by myself, so when ‘G’ [dad] came home, I would be crying or shouting or I’d lash out at him. So it was a very difficult time. I was older too, we were both older. You see, I was 41 and ‘G’ [dad] was 49 when ‘A’ was born, so we were
old and got tired quickly. With a new baby it was a major change for us because we had both had long careers, and we were not prepared for a baby. Then I developed this chronic fatigue and when we were in the middle of this ... when 'G' [dad] was all tied up with his own job, his own future, ‘A’ developed diabetes. I had given up my job because all I could think of was my precious little boy with whom I’d been blessed in my middle age. I had to take care of him, so I didn’t think about ‘G’ [dad], and we were just going from bad to worse. We couldn’t communicate, we would fight all the time. Then in the end, this diabetes got to us both, we decided to sit down and talk about it and see what we could both do, what was best for our son ‘A’ (beginning to cry). Then we decided we couldn’t fight anymore. ‘A’ needed us both so we must be good and kind to each other (sobbing) and so once we knew we had to work together, everything got better. ... So it was the diabetes that did it I think, our need for each other to support and help ‘A’ made us support and help each other. So I’m sure the diabetes brought us back together and ended our emotional crisis.

Although many parents discussed the need to understand and help each other, few did. Instead, the infant’s or toddler’s diabetes tended to drive families apart.

Another change in roles and relationships that resulted in conflict and friction was the change in grandparents or extended families. Although some grandparents were described as very understanding and supportive, most experienced an emotional crisis of their own and were unable to provide the support required. As one mother explained:

M: To begin with, they were all hysterical, just like us. All they ever asked was, when will it be going away. They used to ask me when it would be gone, and I used to try to explain that it would be lifelong, but they didn’t believe me. ... and so when I say lifelong they say, "Oh no, you’re wrong! It will go away." I got tired of arguing, so now when they ask me when it will go away, I just say "I don’t know", because I’m sick and tired of arguing and they don’t believe me.

Parents were left feeling sad and frustrated and lonely and misunderstood. Most concluded that diabetes was a monster that continually threatened their ability to be positive or normal. A father concluded:

D: It really gets us down and we fight, it’s a shame really because we try to be so positive and want him to know he can have a normal life and do anything he wants to do, but it’s difficult to be positive with this monster continually hanging over your head.

To many families, diabetes was perceived as a monster.
Emotional responses, and conflict and friction, left parents feeling emotionally drained and physically exhausted. The parents described this period of their lives as being one of surviving and not really living. However, they were committed to ensuring the well-being of their young diabetic child.

**Coping Strategies Employed by Parents to Manage the Situation**

To manage the child's daily regimen parents employed a number of coping strategies that included being methodical, being vigilant, making decisions, sharing responsibility, interacting with health care professionals, trusting others, identifying needs, reducing stress and maintaining hope. These behaviours were perceived as necessary by parents to ensure the health of their infant or toddler.

**Being methodical and vigilant**

Parents considered being methodical and being vigilant as essential elements of the management regimen. These coping strategies were applied to tasks such as preparing food, getting the child to eat, managing hypoglycemia, dealing with unpredictable blood sugar readings, monitoring blood sugars and giving injections.

During this phase of the parents' experience, flexibility was not perceived as a major option in the management process. Consequently, parents tended to mould their lives around the young diabetic child's needs. Being methodical included always having meals and snacks on time, always measuring food accurately, always testing blood sugar levels before meals, and giving insulin injections at the same time each day. As one father explained:

_D: We know how careful we must be with food, insulin and blood tests. After all, we know our son's life is in our hands. His future depends on us._

Another father explained:

_D: We never miss a blood test before meals ... it's our lifeline to knowing where her blood sugar levels are ... we judge her moods and her needs by her blood sugar levels._
Because meals and snacks occurred six times a day, parents explained how methodical they were about ensuring that these meals and snacks were on time.

D: We always worry about three meals and three snacks on time every day. Food measured correctly. We can’t go into fast food restaurants yet.

Even when a little flexibility was called for, parents had some difficulty with this. As one mother explained:

M: You need to be so methodical. Plan everything ahead. Like the day they had the picnic for the play group in the park. Lunch for all the kids was at 11 a.m., but ‘S’ couldn’t eat until 12 noon. All the other kids were drinking pop and eating candy bars, so I planned a special snack for ‘S’. We then waited until 11:45 ... it was close enough. So we did a blood test right in the park, and then she had her lunch. It didn’t bother her; she was happy with her cucumbers for snack ... but it bothered me inside. ‘S’ is used to the routine, but for me it’s very hard. I wish I could have changed it so that she could eat with the other kids.

Another mother said:

M: Birthday parties are hard. I worry and plan for days before we go. Sometimes I think it would be easier not to go at all ... At the clinic, they told us he could have a little cake if I took the icing off ... So I say, "Mommy will fix your cake" ... and I expect him to scream and fuss like he so often does. However, he generally takes one bit of cake, then runs off to play ... the toys are far more interesting. So sometimes I worry for nothing.

Most parents described how they methodically measured all food, and how frustrated they became if the child didn’t eat.

M: We are very strict, we measure and weigh everything, except half a banana ... you can’t weigh that ...But sometimes he won’t eat and I’m thrown into a panic. In the very beginning, we fed him constantly. It was a crime, but we didn’t know what else to do ... we knew he had to eat or his blood sugar would go low.

The parents’ frustrations often led to inappropriate coping behaviours, such as strapping the toddler into a high chair and force-feeding. However, during this phase of the experience, parents were often too stressed or inexperienced to consider alternatives. Parents of a two-year-old who had been given insulin and then refused to eat explained their actions this way:

M: We were in total panic. We felt so guilty. So bad. I remember him sitting in the high chair and we strapped him in and just force fed him.
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D: Yes, it was ridiculous. Luckily he was young enough still to be in a high chair so we could strap him in and we took it in turns sitting beside him forcing food in hour after hour ...

Another mother explained her actions this way:

M: In the beginning, I was so scared of low blood sugars, we’d strap her in her high chair and feed her continually. It wasn’t like feeding our child ... it was like feeding this monster called insulin ... or like feeding the diabetes ... we were so inexperienced, we didn’t know what else to do. You see, once you’ve given all that insulin in the morning, you know that without food, the blood sugars will go low.

In contrast to these strategies, one mother did describe some innovative techniques used to ensure her young daughter got the food required. Leaving small bowls of food around so that her toddler could help herself was an unorthodox method, but it worked. The mother explained:

M: Well, I was exhausted with all this fighting over food. It was becoming such an issue. A constant battle ... So now I put little cookies or rice crispies and raisins into bowls and put the bowls in ‘G’s’ favourite spots around the house. I don’t say anything, but I keep checking the bowls, and eventually everything’s gone ... I don’t expect the diabetic team would approve of my tactics, but it works for me.

A mother whose toddler had initially craved food, and displayed major temper tantrums if he couldn’t eat, described her method of coping. The family only ate at home, where food could be controlled. They did not eat out.

M: Generally, we don’t go out for meals anymore. If we are invited out, we eat at home first, then go when the other meal is over. If guests come here, we only eat what ‘C’ can eat ... Otherwise, I wait until he is in bed, and then we have friends in to eat. I feel so mean denying him food. It’s very hard, it’s very restricting; after all, eating food together should be such a pleasure ... but it’s the best way I can do it at the moment. I know I’ll have to change, but I’m waiting until I understand more ... this saves hassle at the moment.

Although never going out for meals was a coping behaviour that took away a lot of pleasure and caused stress for the mother, it was a preferable alternative to the hassle and trauma of denying her young son food that he should not eat. For one father, who had trouble accepting his toddler’s condition, the opposite strategy was used. He deliberately took his son out to eat ice cream and purposefully went overboard with amounts eaten in an attempt to compensate for foods his son could not have. This coping
strategy met the father’s need to provide pleasure for his child, but caused stress for the mother, who was conscientiously trying to maintain her son’s diet. She explained:

M: ‘G’ [dad] has still not come to terms with ‘A’s diabetes. He procrastinates over injections and blood tests because he is terrified of needles. All that’s left to me. But with regard to food, when I am at work, they go off to a restaurant and eat ice cream, or whatever. ‘G’ knows ‘A’ can have ice cream on his diet, but he never considers the amount. I know they eat lots ... You see, ‘G’ [dad] is a gourmet cook, and this restricted diet is devastating to him. Going out for ice cream is one of his ways of compensating, making it up to his son, making it all right ... I just wish he would order small ice creams.

The mother of this young child used another coping strategy if her small son’s blood sugar levels went too high following the extra food. She would send father and son out to the park for extra exercise and activity, because she knew this would help to reduce the blood sugar levels.

Consistently feeding the child at the correct time was a strategy used by most parents to avoid hypoglycemia. The fear of low blood sugar reactions was a motivating factor in maintaining a regular food intake for the child. If the child wouldn’t eat, it threw parents into a panic. However, despite conscientiously following this part of the management regimen, some toddlers did experience hypoglycemic episodes, and parents had to know how to cope with them. Parents had been taught to carry an emergency kit with them wherever they went. The kit contained a fast-acting sugar, some starch and protein, and monagel reaction gel. All parents described faithfully carrying this kit wherever they went. However, the first encounter with a hypoglycemic episode evoked total panic in parents who realized how vulnerable their young child was. One mother did explain how she managed the situation and afterwards felt very relieved that she had saved her child from a seizure or coma.

M: It happened so suddenly, right in the supermarket. I was terrified; there was no warning ... luckily I knew what it was, knew what to do. She went so pale, so shaky and one of the tellers wanted to call me an ambulance ... but I felt in control ... gave her juice to drink and then monoject. I was quite calm at the time, but afterwards my knees were like jelly. I called ‘C’ [dad]; I had to talk to someone. I was so scared.

Calling someone for support following the incident eased the parents’ stress and assured her that she had handled the situation adequately.
For other parents, dealing with the first hypoglycemic episode reminded them of the unpredictable nature of their child’s diabetes, and made the mother aware of the responsibility of caring for a toddler with this condition. The mother explained:

M: You see, it comes so suddenly and they are too little to warn you ... to tell you. It was so unexpected, just before lunch, but lunch wasn’t late or anything. Her head was suddenly dropping; she couldn’t stand. We’d never seen it before, but we quickly got juice into her and didn’t even take a blood test beforehand. Once she came round, we did a blood test and it was only 3 (mmol), even after all the juice — so she must have been low ...

Maybe if she’d been older, she could have told us she was feeling funny, but she isn’t old enough ... we have to be able to think for her, anticipate for her and keep her safe ... it made me think I should be the one to care for her always ...

Another mother who had previously experienced hypoglycemia in her toddler used the coping strategy of always sitting outside her young son’s playschool room in case the child went low. Because she had difficulty trusting others, this strategy eased her stress. The father explained:

D: ‘D’s [mom] so afraid she sits outside the playroom door for the whole two hours our little boy’s in play group. She feels better that way because if ‘S’ went low and the teachers didn’t notice, she’d be right there. You see, they have so many children and he’s so young, he couldn’t tell anyone he was low. So this is ‘D’s way of coping. ‘S’ can still be in his play group, but help is close at hand if he needs it.

For many parents in the study, the fear of nocturnal hypoglycemia initiated new strategies. Some parents installed intercoms or alarm systems into the child’s bedroom so that every movement or noise made by the child could be recorded.

M: It’s very good; the alarm is very noisy, it’s fixed in her crib and I can hear her every breath. So although I’m not in the room I can detect any changes in her breathing, any crying, any signs she could be going low ... it’s comforting.

Other parents moved their own bedrooms to be closer to the child, or moved the child’s bed into their own room. Many parents got up in the night to check their child and often set the alarm for 2 a.m. or 4 a.m. in order to check a blood sugar level. Some parents took turns sleeping in their child’s room, particularly during the first few months post-diagnosis. Two mothers, whose husbands were away or else worked night shift, became almost paranoid with fear. They felt more comfortable if they had the child...
sleep with them, and each kept injections of glucagon prepared beside the bed. They also had supplies of juice, monogel and food on the bedside table. Each acknowledged feeling safer with their child beside them, but also admitted to being in constant emotional turmoil in case their child suddenly awoke and experienced a hypoglycemic seizure. Some parents kept their child’s blood sugar high to avoid this. Parents explained their reactions this way:

M: Also, you know another struggle I have with myself and ‘A’ since ‘G’ [dad] went is a fear of managing night-time insulin reactions alone, so ‘A’ sleeps with me most nights. With him beside me, at least I feel safe. I know I’d hear him if he suddenly woke up or started to seizure. I keep the Emergency Kit and the glucagon right beside me so I can use it immediately. But night time insulin reactions are a constant fear and impact on my emotions and on my life. I used to fear crib death. Now that fear has changed to a fear of night time insulin reaction, so I think I kept his night time blood sugars too high because I was scared of lows. Then he always soaked his diapers and woke up thirsty instead, so you can’t win; no wonder I seem chronically fatigued!

Although this was an appropriate coping strategy to eliminate the fear of a hypoglycemic episode, it inappropriately led to symptoms of hyperglycemia. The resulting loss of sleep for the mother and child due to thirst and wet diapers for the toddler during the night created new problems and contributed to chronic fatigue for the mother. However, fear of nocturnal hypoglycemia led other parents to similar actions. Another mother described her fears and coping strategy this way:

M: Well, to be honest, I worry about it [hypoglycemia] all the time. You see, ‘S’ [dad] is on graveyard shift as you know, and I’m home alone at night with the kids. If he went low at night, what if it happened in the middle of the night, how would I know, how could I tell, this is what concerns me!

So when ‘S’ is away, I have ‘M’ [five-year-old daughter] come into my bed, and then ‘Ch’ also comes in. I feel better and sleep better then with him by my side. I feel I’d know if anything was wrong. You see, I know the low blood sugars can send him into a coma and this worries me.

Sometimes the parents’ actions taken to prevent severe hypoglycemia were not effective. In this case, the only recourse left to parents was to seek assistance from health care professionals. If parents were unable to control low blood sugar levels, they needed help. However, seeking help led to feelings of inadequacy.
Breast feeding or bottle feeding young infants posed a major problem for parents. Getting an infant to feed consistently and on time was virtually impossible. Often it was necessary for parents to consult health care professionals. One distraught mother of a very young infant described her efforts to feed her seven-week-old chocolate chips and honey, because he wouldn’t breast feed. This mother acknowledged that health care professionals would not approve, but it was the only thing she could think of doing, given the tension and panic when her baby wouldn’t feed.

M: When he was low and irritable, you could feel the tension rising between us two [mom and dad]. Of course, we were exhausted and frustrated ... it was 2 a.m. but we dared not sleep ... He usually goes low at night, so we just sat up and let him suck on chocolate chips and honey. I know they wouldn’t approve at the hospital, but what do you do? It was our tension ... it’s our baby.

Other parents, whose infant had been diagnosed at a very early age, described their feelings of helplessness when their infant developed low blood sugar readings and they were unable to get the baby to feed. This family dramatized the point when their seven-month-old developed "flu" and began to vomit. The parents described the utter panic they felt, because they had already given the insulin, yet couldn’t even get fluids into their infant. The only recourse for these parents was to hospitalize their infant again. For the mother, who was a registered nurse, this need to rely on others for her infant’s survival constituted defeat, and rekindled all the fears and anxieties of their child’s initial hospitalization. She described her feelings of taking her baby to the hospital for the second time in less than two months, and of wondering if life would always be like this, with constant crisis. Unfortunately, in this situation, the coping behaviour of seeking professional help was the only available recourse to the parents.

M: After only six weeks he developed a "flu" bug. He was so sick he couldn’t keep anything down. Initially his blood sugars were sky-high, then they went all over the place, up and down, then they went so low we couldn’t cope. He was so little we hadn’t a clue what to do, so we took him to Children’s Hospital. He needed I.V. dextrose, and for the second time I thought he might die. I felt defeated. I felt panic. It wasn’t how I had planned to cope at all.

The father of this infant then described another time that they were required to hospitalize their son again.
D: The next time we had to go to emergency ... I think his blood sugars were too high and he had ketones, yet his symptoms were the same ... vomiting and unable to take his bottle. This diabetes is so confounding, so unpredictable. We felt defeated .. but we thought he could go low again, just like the last time, so we knew we couldn’t cope ... we needed help.

This fear of not coping and the fear of the child becoming severely hypoglycemic led parents to being totally vigilant with their child’s management regimen. Parents perceived their child as being totally reliant on them for their very survival. Consequently, being vigilant was a necessity. One father explained:

D: We must be totally vigilant with insulin, blood testing and food. We know 'D's life depends on us. So we meticulously clean and calibrate the blood glucose monitor so that all the readings will be correct ... you see we rely on that monitor implicitly ... it’s our way of knowing if he’s up or down, and what help he needs from us. We care for that monitor just like you taught us in the hospital. We know a mistake on our part could lead to an inaccurate reading and a possible crisis on our hands.

Care of the blood glucose monitor constituted an essential part of the management regimen for families, because this monitor served to inform the parents of their child’s condition. Parents felt responsible for maintaining the equipment. This way, they could avoid crises for their children due to inaccurate blood glucose readings. Another form of vigilance was for parents to be in a constant alert state, watching for any signs of hypoglycemia in their child. One parent explained:

M: We are constantly watchful ... constantly on the alert. Never relaxed really. Looking for signs ... is he pale, is he irritable, if he’s irritable, what is the blood sugar reading? You see things happen so quickly, you have to be aware, you have to be alert, you have to think clearly and act quickly ... always be prepared for a crisis.

This vigilance also applied to mixing, measuring and administering insulin to their child. Although this procedure was perceived as the most traumatic for all parents in the study, each family recognized it as the means of their child's very survival. Consequently, despite all the struggles and problems surrounding insulin injections, each parent acknowledged and explained its importance, and recognized that they had little choice in the decision-making process with regard to giving these injections.
Making decisions

During the early months following their infant’s or toddler’s diagnosis, the process of making decisions about giving insulin or managing any other facet of their child’s care was fraught with trepidation and emotion. Parents’ initial reaction to their child’s diabetes had been one of disbelief. They constantly asked themselves how they could possibly manage all the blood tests, insulin injections and meal planning, while simultaneously meeting all the other needs of their child. However, even within the hospital setting, the decision-making had been simplified for parents. Suddenly, parents realized they had very little choice in the matter, that their child’s entire future depended on their ability to cope, and that as parents they were responsible for their child’s survival.

With this decision-making taken out of their hands, the parents faced the responsibility of managing their child’s care with varying degrees of resignation. While acknowledging that they had no real choice, parents had to decide how best to handle insulin injections as well as other essential procedures. Because insulin administration was perceived by most parents as the most problematic for their infants or toddlers, the majority of accounts began with this procedure. As one parent explained:

M: When we came home from the hospital, we couldn’t believe all we had to do for our child. ... We were already exhausted and stressed out, and you see I am afraid of needles ... they scare me ... my stomach aches and I feel sick, so I didn’t see how I could do all those injections. I thought the needle would break off under the skin if she struggled and cried. ‘C’ [dad] was calmer. However, we made the decision that we just had to do it.

You see, we realized ... that without her insulin ‘G’ would get sick and die, and that she was relying on us to help her, so no matter how much she struggled and cried we just got on with it.

This mother continued:

M: In the beginning ‘C’ [dad] was late for work every day. It took two of us to give the insulin. We would lie ‘G’ down on the floor and hold her down and just give it. I was dying inside, crying inside ... our little girl ... but we knew it had to be done. Often we didn’t even say anything, we didn’t explain, we just held her down and got it over with.

Another parent explained a similar strategy:
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M: We really had no choice ... we just had to do it ... even with all the screaming and squirming we had to give the insulin. She would cry and say "no pokey", "no pokey today mama". Then I’d tell her how I hated it too. I thought if she knew I hated it, then she wouldn’t hold it against me ... I felt so cruel. But we’d hold her down and give it. There really is no reasoning with a two-year-old. We did try singing and bubbles and all those other tactics, but the best is just to get it over, then a big hug and forget it.

The parents all described their need to hold the child down and just get on with the injection and get it over with. All the tactics of singing or blowing bubbles didn’t seem to work in this age group. In the end, the best method was to restrain the child and inject as quickly as possible. Most parents felt cruel and badly about hurting their child, but overcame these emotions sufficiently to inject their child.

In one family, the toddler himself helped his parents to cope initially with the task of giving insulin. The parents described their experience with a two-year-old son who seemed to sense their fear. Consequently, the child didn’t fuss or move during injections, even though tears welled in his eyes. The parents explained:

M: It was as if he sensed our stress and fear. This blond-haired, blue-eyed angelic-looking little boy just sat there. Our hands shook and we told him we loved him and he didn’t even move. Silent tears poured down his cheeks, but he didn’t make a sound.

D: Yes, it was as if he also knew we must do it, as if his body craved insulin, so he had to take it.

The procedure of obtaining blood samples from the young child’s fingers was perceived as less traumatic by most parents. Each explained how they let their infant or toddler become a little more involved with pushing buttons and watching the results appear on the dial. In fact, it was often the child’s resignation and acceptance of this procedure that affected the parents’ mode of coping. One mother explained:

M: I find it difficult to handle. This little child ... just holds up her little finger and says "poke here mama". I do it with a smile and a nod, but I’m crying inside having to poke this little kid 4 times a day.

A father explained why they continue to do blood sugar readings 4 times daily, and often during the night too.
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D: We rely on the blood sugar readings so implicitly we couldn’t not do them. We take the meter everywhere. To the park, to the beach, into the garden. We have a special bag that goes everywhere with us. It’s got emergency supplies and the blood meter ... We religiously test 4 times a day and more often if we are concerned. We often get up and check ‘S’s blood sugar in the night. We sleep better if we know he’s O.K. This is our lifeline, our measure of control ... it gives us confidence. It’s powerful to think a little meter can give you so much information.

Most parents relied on the blood sugar readings in order to make any semblance of sense out of their child’s diabetic control. One of the reasons for relying so absolutely on blood sugar levels was the young age of the child and the consequent inability of the child to identify or convey any symptoms or problems. Parents described their feelings of confusion when a young child’s blood sugar reading was less than 2 (mmol/L), yet the child was still running around. One mother explained:

M: Without the monitoring I’d be totally insane. You see, she cannot tell me how she feels ... she does not even recognize a problem ... I have to be my child’s eyes, my child’s mind ... I have to anticipate for her, think for her, respond for her. Without my help she couldn’t survive ... I virtually live her life and judge her moods and needs by the numbers on a meter ... It’s frightening, an awesome responsibility. With a blood sugar of less than 2 (mmol/L) I know I have about two minutes before she’ll crash.

The need to anticipate every move for their child was a coping strategy employed by all parents. One mother, who was more philosophical, admitted that all parents of toddlers had to do the same whether or not the toddler had diabetes. Parents were still responsible for protecting their young children from harm. The only difference with diabetic toddlers was the difficulty differentiating normal toddler behaviour from diabetes-related behaviour. Parents explained that with a temper tantrum or unacceptable behaviour in a normal toddler, the parent could take action such as discipline or ignoring the behaviour. Whereas in a toddler with diabetes, the temper tantrums or irritability could be due to high or low blood sugars and, if this were the case, discipline would be unjust and ignoring the situation could be disastrous. Parents described their need to be understanding.

M: We have to test his blood sugar in order to understand his moods ... then he battles with us over the monitor ... I want to discipline him but I know it’s not fair ... so we motor on through ... I try to give him love, to remain patient, but it’s exhausting.

D: We don’t know if it’s the "terrible two’s", or diabetes.
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Other parents had to stop themselves from being overprotective. They still perceived their child as not being entirely strong or well, and the natural tendency was to overprotect.

M: Well, he is only two and we tend to still feed him because he will let us. We don’t always let him run with the other kids and I know we don’t always encourage him to do things. You see with diabetes the natural tendency is to overprotect him. We both feel very responsible for his illness, and for his care, so we don’t give him any independence at all yet. We’re not able to.

Most parents tended to feel a major responsibility towards their infant or toddler, and felt impelled to share management of the child’s condition.

Sharing responsibility

The need for teamwork and sharing responsibility was articulated by the parents as imperative to the long-term health and well-being of the young child with diabetes. Parents described their own shared responsibility on a day-to-day basis, plus their need to share responsibility with health care professionals.

In order to assume their portion of responsibility for the young child’s care, the fathers in each family were required to make some adjustments in their own lifestyle and socialization patterns. As one father explained:

D: I rarely go out now. I used to go for a drink with mates after work, or on weekends, but I rarely do anymore. You see, ‘K’ [mom] needs my help. She’s stuck inside with ‘T’ all day, so when I come home, she needs some respite. So I take over.

Another father explained:

D: It’s different now. I go to the park with my son instead of to the club with my friends. ‘R’ [mom] needs a break, so I take over. We share the load and responsibility.

A third father stated:

D: I used to have my head full of knowledge. I’d take courses, I’d socialize. Now I rush home every day. My head’s full of diabetes. I need to do ‘R’s injection and blood test. There’s no room in my life for courses or socializing.

Another father explained his responsibilities like this:

D: I come home late sometimes during the week, but on weekends I take over. After all, ‘K’ [mom] has coped all week ... now it’s my turn.
And the mother of a two-year-old described sharing responsibility this way:

M: I have weekends off. Once C [dad] gets home I know he'll take over. Injections, blood tests, food, everything. I become a normal person again, not a diabetic child's mom. It's such a relief. 'C' is so good ... after all, he's had a busy week too. It takes us both to battle this thing, to get everything done.

The necessity to share responsibility was perceived by parents as being due to the magnitude of the general responsibility of caring for these young children. Parents described the responsibility as never-ending, never letting up, never going away and lasting twenty-four hours of every day. Part of their responsibility was trying to stabilize their infant's or toddler's blood sugar levels. One mother explained:

M: It's really never-ending, never goes away. Sometimes you want to say "no, not today", "let's leave it today", but you know you can't, you never relax, it's either insulin, or blood testing, or a meal, or a snack, or a low blood sugar or a high blood sugar to take care of. You can't get away from it.

Another parent described the need to accept responsibility this way:

D: We feel so responsible. Sometimes, even when we've done everything right, the blood sugars go too high or too low. You become frustrated, you feel responsible and you plan for some exercise if it's too high [blood sugar] and some juice if it's too low.

Although parents became frustrated over their own inability to stabilize their young child's blood sugar levels, they never stopped trying. They rationalized that part of their responsibility was to seek professional help in managing their child's condition when necessary. Thus, parents perceived an alliance with nurses, doctors and dietitians as essential to the well-being of their child. Although they felt responsible for the overall day-to-day care of their child, this acceptance of shared responsibility provided some security. As one father explained:

D: We know we are totally responsible, after all, he is our child ... but we need the nurses and doctors for support, we can't handle this alone ...

As it is, we feel an awesome responsibility with this powerful substance called insulin to play with ... we need to know what we are doing.

Parents particularly felt the need to have someone share their responsibility should their child become ill.

At this time they looked for support, and explained their own feeling of inadequacy to manage alone.
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M: Of course when he’s sick, I don’t fool around. I’m straight on the phone to the clinic. It’s too much of a responsibility to have a diabetic toddler ill ... I don’t know enough about insulin, about making changes, giving extra fluid. If he vomits, I need backup, someone to show support and relieve me of some of the responsibility.

When seeking relief from some of the responsibility for their child, parents relied heavily on members of the diabetic management team who had taught and counselled them during their infant’s or toddler’s initial hospitalization. Because the fine tuning of insulin adjustment for a child takes place at home and not in the hospital setting, parents make use of a telephone service that links them with the doctor, nurse, dietitian or counsellor on a 24-hour basis. This phone line was perceived as a major source of support during the parents’ first stressful months of caring for their young child with diabetes. Communicating by telephone and seeking advice from experts relieved parents of some of the responsibility and decision-making with regard to their child’s management. However, parents reported varying responses to this form of interaction which seemed to be related to their own needs at the time of using the service. Although the phone service was intended to be used for insulin adjustments and receiving advice on management problems, some parents perceived the advice they received as being strictly technical and not personal enough to meet their needs. One mother explained:

M: When we first phoned in for advice, it was all very technical. Just what are the blood sugar results and reduce the insulin ... mind you, it was over the Christmas holidays, and we got a different doctor each time. There were no nurses or counsellors to talk to, so maybe this all added to our problems.
... I guess what we were looking for was someone to ask, how are you? How are you managing as a parent? Someone to share our emotional experiences and take responsibility for our needs — not just our child’s needs.

Other parents described their experience with this service quite differently. They perceived the service as a lifeline, a constant source of information and a means of relinquishing some responsibility for their child when they went out. These parents left the telephone number with babysitters or relatives in case of an emergency situation arising. However, mostly they used this form of alliance to absolve themselves from some of the decision-making regarding insulin adjustments for their toddler. One mother explained how she handled necessary changes in insulin for her child:
M: Let's see, I can handle it. However, I'm still a novice, I'm not very good at Math you see... so I don't understand the differences between the N.P.H. and regular insulin, or which is clear or cloudy, and I have no idea which dose to change. I just call the clinic... that's my lifeline. That hot line is wonderful... I know I can call anytime and someone there knows what to do, they know what they're doing and what to tell me. I don't know if I'll ever know which insulin to change.

The necessity to rely on health care professionals for help and guidance led parents to discuss the following coping strategy.

**Interacting with health care professionals**

Parents' interactions with health care professionals were deemed essential by all parents in the study. Parents relied implicitly on these experts for advice on managing their child's diabetes. Generally, interactions were considered to be supportive and helpful to parents. However, sometimes parents expressed an opinion that not all the experts truly understood the parents' needs. While acknowledging that technical matters such as blood sugar readings and hemoglobin AI, results were discussed in great detail and competently acted upon, parents also suggested that emotional needs of the parents were not always met. While having confidence in those responsible for their child's health, parents did discuss some lack of understanding on the professionals' part with regard to parents' needs and expectations.

One parent discussed an interaction with a health care professional during a follow-up clinic visit. The expert had listened to the mother expressing her feelings of "being trapped" and "tied down." The expert then suggested to the mother that it would be therapeutic for her to leave the child and get out sometimes. Although this was a logical and well-founded suggestion, the mother was infuriated and frustrated. She explained how difficult it was to find a babysitter willing to care for a diabetic toddler.

M: They didn't understand the problem. It's easy just to say you have to get out, without any thought of how. No-one understands that people are scared of taking care of a diabetic child. No-one understands that parents are afraid of trusting their child to someone else. Of course I'd like to get out, but I want someone to suggest how... to provide the means... not just say, this is what you should do.
For this parent the health care professional was unable to provide sufficient information to help solve the immediate problem.

For the most part in this study, the parents identified nurses and dietitians from the diabetes team as being the most supportive in meeting their needs. Parents felt comfortable and trusted these experts, who had been their main contact and principal educators during their child's hospitalization. Parents were familiar with those health care professionals and enjoyed the interactions by phone or during clinic visits. Because the nurses had taught the parents the techniques of insulin administration and blood glucose monitoring, these were the experts to whom parents turned for support and advice regarding problems with these procedures. Dietitians who had taught parents how to handle the daily meal planning were also professionals sought out by parents to discuss dietary changes or the child's eating problems. The availability of a counsellor to offer support was seen as a major benefit by these parents. Physicians were perceived as experts who were essential to the long-term health and growth of the child. They were acknowledged as specialists who made necessary insulin adjustments and monitored the child's condition. However, they were not perceived as the primary source of support and were not sought out for day-to-day advice, but instead were relied upon in crisis situations. It should be noted that this situation could be different in other health care settings, where there is no "diabetic team" concept, and where the pediatrician or physician provides most of the basic education and follow-up for families. All the children in this study were followed by the diabetic management team at the same facility.

Generally, despite a few exceptions, most parents trusted the health care professionals involved in their child's care. This trust enabled parents to feel reassured that their diabetic child was properly cared for, and no parent related any story of encounters that would have affected their ability to trust. Confidence and knowledge were qualities considered by parents to be important and enabled parents to feel these experts were worthy of trust.

M: At the hospital they taught us so much. They were so knowledgeable, it gave us confidence. Now when we call even for simple advice, they always know the answers and I trust their
judgement implicitly. I've never questioned a decision they made. Frankly, I don't know if they are right or wrong ... I feel so confused sometimes ... but everything I know I've learned from them, and ‘G’ is surviving, so they have to be right.

One mother did acknowledge trying a different approach:

M: Well, at the hospital, they say under 10 [mmol/L] for blood sugars, but I am so paranoid ... so afraid of hypoglycemia, I keep the readings higher ... I know that doesn't please them, but it lowers my stress and my anxiety. I know they worry about long-term complications and I appreciate their concerns, but basically I am on survival tactics, not really living for the future, just surviving day to day ... so, although I know they don’t approve of my method, I'm too afraid to change things right now.

Other parents wanted more information and more understanding of their problems and experience at home. A mother explained:

M: You see, we go to the clinic. It’s all very technical, very clinical, centred on the blood sugar levels, the HBAI, and the diet. Also, whether ‘D’ has grown properly. It's very focused on diabetes. Sometimes I think, ‘Oh! why don’t they ask me how I feel, ask how are you doing as parents, or what it’s really like to manage all this at home?’ Everyone is very kind and concerned, I truly mean that and they are our lifeline, but sometimes their expectations of us are hard to live up to. I want to do everything right but it’s not always possible. ... That’s why we are really glad you are here, just to listen, just to hear our point of view.

Despite the need for a deeper understanding and more information from health care professionals, parents acknowledged that they relied on these experts for support and couldn’t do it alone.

M: We know that we are ultimately responsible because, after all, this is our child ... but we need the nurses and doctors to support us, we can’t do it alone.

Even when reporting some negative aspects of their interaction with health care professionals, the parents described faith and trust in the experts with whom they interacted.

**Trusting others**

Despite their apparent ability to trust health care professionals, one of the major stumbling blocks identified by parents was their difficulty in finding others whom they could trust. Parents perceived this lack of trust as evolving from their intense fear of hypoglycemia, and difficulty in accepting that others could recognize or treat a hypoglycemic reaction in their child. One mother explained:
M: I think it’s a basic lack of trust. A fear that something isn’t working properly inside ‘D’. It’s something I cannot understand and cannot control totally ... so if I cannot understand, how can I expect anyone else to?

Another mother explained:

M: I’m afraid what will happen if I’m not there. He’s so little, he can’t even tell anyone how he feels. What if he went low and I wasn’t there? I’d never forgive myself. So I’m afraid to leave him ... to let him out of my sight. It causes problems.

Yet another mother said:

M: I’m only just beginning to trust one of my sisters. I have 4 sisters and she’s the only one ... she’s a nurse, and can do blood tests. But basically, I wouldn’t leave ‘S’ with anyone else. It’s either ‘B’ [dad] or me with him all the time ... until we become more confident.

This lack of trust created socialization problems for the parents, and an inability to get out. Several parents did identify this as an issue, and also recognized it as a deterrent to grandparents who shared the parents’ fears, yet may have been willing to learn had parents showed confidence in them. As one mother explained:

M: My mom-in-law is beginning to come round. She’d love to have ‘S’ and she has some experience, because ‘B’s [dad] brother had diabetes. But they live in a small town, and if anything went wrong, who could she turn to? ... I doubt even the doctors up there would know what to do ... so I can’t trust her yet, not on her own ... not unless we are there.

In contrast to this difficulty with trusting others, some parents described their faith in relatives or babysitters to care for their child. This trust appeared to be related to the caregivers’ past experience with diabetes, or the parents’ attitude, values and beliefs about their child’s condition. One mother, whose own mother had type I diabetes, explained things this way:

M: Well, I am still a novice with this, but my mom is an expert. She has diabetes herself. She is the one who told me ‘A’ had diabetes. She is the one who diagnosed my brother’s two children with diabetes ... so she should know what to do ... In fact, she cares for ‘A’ better than I do. She can give shots better and test blood sugars, and I trust her more than I trust myself, really.

The need to get out drove one mother to measures she wasn’t sure health professionals would approve of.

However, this was her way of coping with the situation.
M: You see, maybe I'm wrong but I don't even tell the babysitter that 'G' has diabetes. We don't want to scare them. We get our sitters from an agency ... we book them and pick them up, then we say, 'by the way, 'G' has diabetes ... it's no big deal, but if she looks pale and limp and droopy or behaves irritable ... or begins to stagger, then give her some juice, it will perk her up right away.' We leave them the hospital number because we know someone there can help them even more than we could. They can also call 911. You see, we figure 'G' could choke or burn herself like any other toddler, and a babysitter would have to cope. These are mature, expert babysitters ... so right or wrong, we trust them ... that's how we do it.

No other family in the study explained their experiences like this mother. Her way of coping was to minimize the seriousness of her daughter's diabetes. She rationalized:

M: I think it's only if you make it a big deal that other people will make it a big deal ... so I try to be calm about it.

For most parents, however, diabetes in their child was quite a big deal, and the fear of hypoglycemia was very real and affected their ability to trust others.

Towards the end of this phase of their experience, parents were beginning to realize that their lives could not continue indefinitely in such a rigid, inflexible and emotion-laden manner. They began to identify a variety of sources that could be used for reducing stress, and these sources will be presented in the next theme.

Identifying needs: reducing stress

Parents identified a number of stress reducing strategies. The availability and utilization of these sources determined the parents' ability to cope with their child's management and to meet their own needs. Parents described a need for empathy, understanding and support from others, a need for information, knowledge, understanding, and the need for confidence and empowerment. With these needs met, parents perceived a greater possibility of success in competently moving beyond mere survival tactics, and better managing their situation.

When identifying their needs, families expressed an overriding need for someone to listen to their point of view. Most expressed the benefits and therapeutic nature of the interview process conducted for
this study, and the benefits they had derived from participating. One father explained his feelings this way:

D: What we need is someone like you to come and talk to us on a regular basis ... just to sit and actually listen and let us talk ... you have no idea how helpful it would be. For me to know how 'M' [mom] feels, how she felt, for her to know how I felt ... we've learnt a lot about each other. But a visit like this, every two or three months, to vent our feelings and to let us know ourselves how we actually feel could have incredible benefits ... for when you are in the centre of this, there is no objectivity.

R: I understand.

D: Well yes, for as we've told you, 'M' [mom] just stopped talking, she couldn't communicate with me and I had no way to clarify what she was feeling deep down inside that silence. We are so intense, so focused on the practicalities of what must be done and how to do it that there is no time for each other, no time for yourselves.

M: Maybe if I'd had someone to talk to, to share my feelings with, I wouldn't have hit that depression and I could have killed us, it's very frightening.

One father described how important it is for someone to take time to focus on the parents' emotional state. He explained how alienated he felt because other people are too afraid and don't want to hear. He put it this way:

D: We've actually given up talking about 'A' [toddler] to most of our friends. People are too afraid, they don't want to hear or to get involved ... so having someone who really cares ... someone to listen ... it's so important. Not just a health care professional who asks, "How are 'A's blood sugar levels', or 'what insulin dose is he on now?'", but someone to ask "How are you doing?, How are you coping?, What is it like to manage at home?" I think someone to focus on the parents' emotional state would be so helpful.

Other parents expressed a need for someone who could provide the parents with support and some perspective, particularly during the first early weeks of their experience. These parents described a situation in which they were so consumed by their child's need that they had completely overlooked the need to care for themselves. They expressed a need for someone to be there, to listen, to diffuse tension, to take away some of the responsibility and bring some calm to the situation. They described how grandparents fortuitously provided this supportive relationship and showed concern for the parents' needs
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as well as the child’s. This was perceived as extremely important to the health and well-being of the entire family unit. As the parents explained:

D: We were having great difficulty getting things into perspective. In fact I don’t think we would have, except that fortunately my parents had come to visit. They arrived the day before ‘R’ was diagnosed, and they landed up staying for several weeks. So we were very lucky to have that support. We wouldn’t have survived without it.

M: That’s true, we were literally two incompetents. I was anyway, I was totally incompetent.

D: Yes, I think if my parents hadn’t been here we would just have landed up screaming and yelling at each other. We were so tired, so utterly frustrated, and no-one seemed to understand. Just to try to release some of that tension between us would have led to terrible rows, I know ...

M: Yes, but ‘H’s [dad’s] parents maintained some normality for us. They made up a schedule for us and ensured that we ate and slept at intervals and prepared meals and brought some calm to the situation.

Consequently, the need for someone to care for the parents as well as the child was identified as a source for reducing stress. Several families identified a need for the parents’ position to be understood and appreciated. The mother of the family whose parents had offered support explained it this way:

M: But you know, our parents said that if they hadn’t been there and see what it was like for us, they would never have dreamed it could be like that, and would have wondered what all the fuss was about. So what we need is someone to understand our perspective of the situation.

Other parents described the same need, but from a different perspective.

M: No-one knows what we go through. Our families realize we are busy, but how can they understand unless they’ve really gone through it? What we need is a support group of parents who have all had young kids with diabetes. Then we’ll each know what the other has been through. Even just another mother to talk to on the phone ... to listen and say they understand.

One family described leaving their toddler with good friends for a prolonged period of time, and the emotional reaction received from the friends on their return was quite astounding. The mother explained:

M: When we got there to pick ‘R’ up, my friend burst into tears. I thought something had gone terribly wrong while I was away. Then my friend explained how sad and frustrated and sorry she felt for us all ... she had no idea what ‘R’s management involved, or the amount of stress we must continually experience.
Parents also explained a need for health care professionals to better understand the complexity of caring for an infant or toddler with diabetes at home. They identified the need for information about support and respite services for parents. One mother explained:

M: What we need is information about available babysitters, or the names of organizations that could help us... It's no good the clinic telling us we have to get out, unless they can provide us with someone capable of caring for our child... we really need a list of other parents with small children with diabetes so that we can form a support group.

Another mother expanded on the need for such a concept:

M: We need support, information about people in the community who could help. You see, sometimes we think we are the only ones with such a small child with diabetes... little ones have so many different needs... what we require are parents with the same problems who can get together and support each other, even if it's only by telephone.

D: Yes... we need a network of parents going through the same thing... to offer each other support and advice... or even to sympathize because they've experienced the same thing.

Other parents sought information about community resources, public health nurses, or other professionals, who could provide information on related infant and toddler needs. One parent explained:

M: Well, it was strange, really. The public health nurse called in on account of 'K' [younger sibling who did not have diabetes]. She didn't know about 'D's diabetes. However, she became a tower of strength, phoned the clinic at the hospital to learn all about diabetes, told us about immunizations, which had really concerned me since 'D' developed diabetes, and offered to look around for babysitters or other forms of support.

The father interjected and explained a need for information regarding financial services and help.

D: Yes, and she offered to help with financial services. You see, we are new to this province, just getting established in a new job... we don't know about what financial services are available. Syringes and insulin are so expensive. They did explain some things at the hospital, but we were so stressed it's hard to remember. We need backup at home because, even when we return to the clinic, we are often too stressed to remember to ask... and being new in the community, we don't know who to ask.

As well as information on support services available, parents identified a need for increased knowledge and understanding of their child's condition. Although the parents had been taught the basics of diabetic management in the hospital, much of the learning had taken place during a time of great emotional stress. Consequently, parents had not retained all the knowledge and, in some cases, had
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misinterpreted information provided. Parents identified the need for management updates as well as information on parenting skills. One mother explained:

M: In the beginning, we just learned the basics ... survival tactics. What we need now is ongoing information ... a better understanding .. an ability to rationalize — not just blindly do what we were told.

A father explained:

D: Well, we read a lot and learn all about these devices, such as an infrared light to test blood sugars, instead of the finger poke. I know it isn’t available yet, but my parents said they would pay anything to let us buy this for ‘G’. To not have to do finger pokes would be so helpful. However, I don’t understand enough about these things, they sound great but I need more information.

A mother explained about a device for giving injections that she learned from another mother, and would like to have been told about it at the hospital.

M: This other mother, whom I met by chance in the park, told me she used a little injector device to give insulin to her child. I bought one and it’s such a help. I don’t know why they didn’t tell us about it at the hospital ... it would have saved me so much stress in the beginning. Maybe they thought we had enough to learn, but it would have been helpful.

Other parents were still seeking very basic information to help them understand their child’s condition with more clarity.

D: I really need to know more about diabetes. I need to clarify things in my own mind. To understand the difference between Type I and Type II diabetes, particularly when someone tells me they know another person who takes pills ... and why does such a little kid need injections. I need to be able to explain to others how or why.

Parents also perceived increased knowledge and understanding as being essential in order for them to move ahead and to be able to teach others. They also expressed a wish that more direct education for grandparents and babysitters be provided by health care professions. Parents lacked the confidence to teach others themselves, but expressed confidence in health care professionals to achieve this task for them. One mother explained:

M: I’m such a novice, so inexperienced. They expect me to train other people to care for ‘S’ when I hardly know what’s going on myself ... You see, you are so stressed in the hospital, you forget half of what they told you. If they provided education for grandparents and babysitters, then we’d have much more confidence as far as trusting people with ‘S’.
Another mother said:

M: We need the names of organizations or people who can help us to educate others. You see, my parents came to the hospital to learn with us, but they were also stressed out and didn't comprehend a thing.

Some parents requested information in order to prevent them from groping around and making mistakes.

D: I really want to understand, not to grope around. We were taught so much in the hospital but were far too stressed and exhausted to comprehend it all. I really appreciate all the information I receive from the doctors and nurses by telephone ... when I remember a question I just call, they are so understanding.

M: It's like every crisis brings up a new question ... you have got to have the answer, or you make the same mistake, or can't cope next time.

A mother summed it up:

M: The more I know, the better I feel, and the better I cope with the situation.

Another source of information suggested by parents was the need for information on parenting skills and developmental issues for the child. Because the child's development was a major concern for these parents, the ability to recognize normal toddler or infant behaviour and differentiate this from diabetes-related behaviour was deemed a necessity. A mother explained:

M: We don't even know what normal behaviour is for a 15-month-old. Some tips on parenting would be helpful.

A father reinforced this need:

D: We really need classes that deal with the special needs of little children who have diabetes. Their needs are so different from those of older children. We need classes on parenting. This is our first child, and we lack knowledge of normal toddler behaviour ... if we knew what to expect under normal circumstances, it would be easier to recognize behaviour caused by the diabetes.

Parents perceived increased knowledge and understanding as empowering them to handle their child's situation more effectively, and also providing them with a greater ability to trust others with their child. They acknowledged the need for empathy, understanding and support from others as sources to reduce stress and enable them to cope over the long term.
Maintaining hope

The last coping strategy identified by parents during this phase of the experience was that of maintaining hope. Hope was not only an emotional response, it was a coping behaviour, a motivating factor, providing parents with the impetus to maintain their child’s health, and ensure their readiness for the cure that was virtually guaranteed. Each of the parents in the study generated hope for the future. None disbelieved in a cure. The parents’ only uncertainty about the future revolved around their own ability to prevent long-term complications for their child until a cure was found. Few dwelled on the future, and each explained they had enough to worry about just living and surviving day-to-day without worrying about their child’s future. Parents rationalized that because their child was so young, some type of cure, or at least major medical breakthroughs in management, would be available to their child before they reached adulthood. The parents perceived their responsibility as one of keeping their child alive and well until the cure was found. Hope generated by health care professionals in the hospital at the time the child was diagnosed was maintained on a continuum by parents during the early months of caring for their infant or toddler with diabetes at home. The following quotes from the parents’ accounts illustrate the parents’ experience:

M: We have so much hope for the future. We know a cure for diabetes will be found before she’s a teenager ... we read all about the research ... we know about the transplant programs and the people at the hospital told us about the possibilities of a cure. That’s what we live on ... HOPE ... you can’t go on without that hope ... that’s what keeps us going day-by-day.

Another mother explained:

M: We still live with hope ... you have to ... without hope what’s the point of all this ... all the anguish ... all the stress ... hope is what parents look for, it’s what keeps them going.

A father whose own brother was diagnosed at an early age and already had some signs of complications expressed his hope for his infant son’s future:

D: Him being a toddler still, of course, we worry about long-term complications. But ... we tend to live for today ... we think a cure will come along. If not a cure, at least something to make caring for his diabetes easier ... You see, so many improvements have been made since my
brother was diagnosed. There was no blood monitoring then, and no devices to help you give needles, and none of the special foods to make life easier ... so things are already better ...

The mother of this child was quite philosophical about the outcome for her child.

M: As I see it, we could all be in an accident, I could bleed to death ... other children die of terrible diseases every day ... so we consider ‘S’ lucky. We can handle diabetes for him and, even if there isn’t a total cure, there will be things discovered to make life easier for him.

One mother who found her child’s management regimen particularly stressful and all-consuming said:

M: When she’s struggling and crying over an injection, and I’m struggling and crying because I have to give it, I think ... this will not go on forever ... when ‘S’ is older, she won’t have to do this herself ... so we do all the work we can to get involved in raising money for research ... that way we can help to ensure there is a cure.

Several families explained that relatives and friends were already getting involved in fund raising endeavours for diabetes research, and that this involvement generated hope due to the enthusiastic reports of the researchers.

In this study, most parents articulated hope and not fear for the future. Most had considered long-term complications. However, uncertainty about the effects of long-term diabetes was minimized, due to the real hope for a cure described by all parents. Because of the infant’s or toddler’s young age, each parent articulated positive feelings that a cure would be found before their child reached teenage years. Consequently, neither their child, nor themselves as parents, would be facing the challenges of diabetic management in the long-term future. The parents’ hope was reinforced by research reports, and reports on advancements in technology and development. Even if an absolute cure was not found, parents believed that methods would be found to minimize or eliminate many of the stressors and demands currently faced by themselves and their young child. This hope, combined with passage of time, and the parents’ increasing ability to identify and meet their own needs, led parents into the third phase of their articulated experience.
Summary

The parents' accounts have revealed that families experience inordinate amounts of stress during the early months following the diagnosis of diabetes in their young child. Much of this stress was due to the liability of the infant's or toddler's condition, and the numerous lifestyle changes required by both parents in order to handle the situation. Many of the stresses and difficulties reported by the parents were related to the extensive and all-pervading management regimen that placed excessive demands on their emotional and physical resources. Parents described many losses in their lives due to the numerous changes imposed by the child's required management. A loss of support systems resulted in loneliness and social isolation and, from the parents' accounts, the younger the child was the greater was the loneliness experienced. Reluctance and fear on the part of relatives and friends to become involved in the child's care contributed to the parents' stress. However, the parents' own inordinate fear of unpredictable blood sugar levels, and their reluctance to trust others with their young child's care, accentuated this problem. The child's inability to convey their own needs, and the parents' need to anticipate and act on the infant's or toddler's behalf, contributed to the parents' stress, and the task of differentiating normal toddler behaviour from diabetes-related behaviour was reported as difficult. Numerous emotional responses to the multiple stressors were experienced, and conflicts and friction due to changes in roles and relationships impacted on the parents' lives. In describing their methods of coping with the situation parents outlined the essential role most fathers played in sharing responsibility for the young child's care, and described the need for constant vigilance as an essential element of managing the regimen. Although parents initially described experiences of simply surviving and not really living, they did identify multiple needs and a number of sources that they perceived as essential to reducing stress and helping them to competently move beyond mere survival tactics and manage their situation over the long term.
Phase Three: Adapting over the Long Term

From the parents' accounts it appeared that this phase of the experience began when families learned to relax a little and to have faith in their own ability to parent a diabetic child. By this time most parents had acquired the confidence and flexibility to begin to trust and teach others. They had begun the process of adapting and incorporating the infant's or toddler's diabetes into family life over the long-term. Increased knowledge and understanding of their child's condition served to empower parents and enhance adaptation. Parents described this phase of their experience as being much easier, and much less stressful. Although new problems, fears and frustrations were identified at this time, families also acknowledged making major breakthroughs in their ability to handle the situation and to cope with problems.

While telling their stories most parents related back to the difficulties and stress experienced in the hospital and during the first months of caring for their child at home. Some described intuitively moving into a new phase of adaptation within six to seven months following their child's diagnosis. Others took more than a year to reach this level. Each parent described a sudden realization that they had come a long way and now felt more in control of their situation and their child's destiny.

When describing this third phase of their experience most parents attributed their current attitude and approach to their increased knowledge and understanding of their child's needs, and how to manage the complexities of the condition. Most parents explained the changes by comparing their current situation to earlier experiences. They explained how time as well as knowledge and understanding had healed. Seeing their infant or toddler grow and develop normally was a major factor that contributed towards the parents' ability to adapt, be more flexible, feel more in control of their situation, and accept their child's lifelong condition.

Although parents still experienced multiple stressors which evoked emotional responses and required coping with, they explained how much easier they found their entire situation now, and how surprised they actually were by the speed with which they acquired the ability to adapt. Making decisions
about their child’s condition or management were now possible and parents felt comfortable with the
decision making process. The following accounts help to explain the parents’ transition to this new level
of adaptation.

M: Well I’ve really surprised myself. You see in the hospital it was hell, I couldn’t cope, I was
totally unprepared ... Then at home I was totally riveted to what we had been taught in the
hospital. There was no deviating, no ability to make any decision. Now I make decisions,
I make changes, and have learned to be flexible.

D: Yes, things are so much easier now than they were. We have a so much better understanding
of his needs now, of his monitoring, readings, diet, and so on.

We were so anxious in the beginning. Now I’m so much more relaxed and know how to
manipulate things somewhat so I’m much less anxious and worried than I was in the
beginning or even four or five months ago.

R: So time has helped and things are easier now?

M: Much less stressful. You see, I guess you get to work with the insulin and make changes
yourself based on blood sugar readings, which I can and do now without calling, and that
understanding and knowledge and ability to make decisions makes it all easier.

Knowledge about the action of insulin, interpreting blood sugar results, and managing dietary changes for
their child contributed to feelings of control for parents and boosted confidence. Another mother
explained the transition this way.

M: I feel more in control now, it’s taken this long, over a year, but of course ‘S’ [child with
diabetes] has developed and grown up a lot too.

One parent described feeling more comfortable.

M: Well after six months I just feel more comfortable and relaxed with the whole routine.

Some parents who had experienced intense emotional turmoil during the first two phases of their
experience described a sudden realization that some of the depression had lifted. A father described his
feeling of having "made it". That he could feel happy and enjoy life again, and that he could begin the
task of putting his family’s life back together. The family had just returned from their summer residence
when the father described his experience.
D: I want to explain what it’s like now with ‘R’ [infant with diabetes]. It’s very different now ...

Well, as we told you, we have a house on Maine Island and just returned from there ½ hour before you arrived. We’d had a bonfire and ‘R’ and I had had so much fun fuelling the fire and laughing, we took about five hours just burning up all the old brush. I suddenly realized how relaxed and comfortable I felt and suddenly I flashed back to last year at this time because I have a bonfire at about the same time each year. It was only three months after ‘R’s diagnosis last year and I distinctly remember fuelling that fire and looking into the flames and thinking I want to just jump in there and disappear and then I won’t have to worry about ‘R’ or ‘M’ [mother] anymore.

You see at that time, I felt shut out and then just looking at the fire and thinking I wanted to disappear was extremely frightening; although it was only a passing, fleeting thought, it was terrifying. Then this year, I was laughing and having fun and I suddenly realized how far I had come, how far we have all come and how time and knowledge and understanding have all healed ...

The passage of time assured many families that their young diabetic child could function like a normal healthy toddler, and this timeframe alone was described by some parents as motivating them towards some flexibility and adaptation. One mother of Italian heritage, who initially had great difficulty accepting her young son’s diabetes explained.

M: In the beginning it was very hard. He was our only son, our family is Italian and wanted to treat him as if he was ill all the time. I thought my son wasn’t normal anymore, that he was defective, and I grieved all the time ... But now time has healed. I see ‘Ch’ running and laughing like a normal two-year-old. I take him to playgroup and his teachers say he is a wonderful little boy ... So I can accept him now, I can accept the diabetes because he’s just like any other child except for the shots and his food and things. Time has healed, for me and my family.

Another mother explained that knowledge and confidence and time all healed.

M: It’s time that helped. During this time ‘S’ has grown and matured a little. I’ve grown, I’ve learned to relax ... I can see that what I do works ... I can actually make a difference and this is satisfying. Mostly it’s because a toddler grows up so much in a short time and you can see that he can be normal despite all the injections and our anxieties.

Despite this optimism and new found confidence, many variables in parents’ accounts were noted. These indicated that, although parents felt more relaxed and were able to achieve greater flexibility in handling the day-to-day management regimen for their child, new stressors and problems did arise that required handling. The mother of a two-year-old, who had been only six months of age when diagnosed, explained things this way.
M: In the beginning when he was so little I found it difficult to inject him and difficult to feed him. Now he's growing and so smart and bright it's almost scary. Of course he's also developed lots of bad habits which often make it more difficult to handle. So although I have more knowledge and more ability I actually think his behaviour is more difficult to handle now because he is so smart.

The fact that the infant or toddler was getting older and smarter contributed to new stressors or accentuated old struggles encountered by parents.

Perceived Stressors

Despite a perceived reduction in anxiety and stress for most families, recurring or new stressors were described by parents. These stressors included issues related to insulin injections, conflicts over diabetic control, issues related to food, behavioral issues, anticipatory worry, and the parents' decisions to have other children.

Because growth and development of the young child was intimately related to all the major stressors identified by parents during this phase of their experience, developmental issues will be interwoven and discussed simultaneously when presenting the parents' accounts.

Issues related to insulin injections

The impact of the young child's diabetes on family life was often compounded by developmental issues in the child. Although parents described the experience of being in control and feeling more comfortable with their young child's management, some areas of the required regimen became more complex because of the child's cognitive and physical development. Parents described issues surrounding giving injections and confrontations over food as becoming more difficult due to a greater understanding on the part of the toddler or an increased physical ability to resist.

Insulin injections had been described as a major sources of stress by parents throughout the first two phases of their experience. However, although many parents had anticipated that this procedure would become easier for themselves and for their child over time, this, in fact, was not always the case. From
the parents’ accounts it could be concluded that as young infants matured both physically and cognitively
the parents’ control over their child’s behaviour and responses diminished. The utter frustration of an
ongoing struggle with a stronger and loudly protesting toddler reduced one mother to despair. She
explained that things had not become easier but were in fact contributing to recurring stress.

M: Well as you know ‘S’ [infant with diabetes] always struggled but when she was only fifteen
months we’d hold her down, get it over with, then give her a big hug. Now she’s older she’s
fighting more and she kicks and screams and runs away. She fights so hard it has become
a major source of stress to me. I realized she is growing and trying to assert herself but I
wish, oh! how I wish there was some way I could reduce this trauma for both of us.

R: It must be very hard.

M: Oh! yes. Of course now ‘S’ can talk as well. A few months ago she just cried. Now she
screams "no, mommie, don’t, you’re hurting me, no, no, don’t do that" and one day a
neighbour heard and thought we were abusing ‘S’ and reported us to social services and they
sent a social worker around to investigate. Can you imagine my devastation? They were very
apologetic in the end and had no idea ‘S’ had diabetes. But I began to wonder am I abusing
my child, how can I handle this so that she doesn’t scream, what am I doing wrong that even
the neighbours hear her and call social services? Here we are, two professional parents doing
the best we can for our child and we are accused of abuse.

... and I was totally devastated ... after a year of struggling to keep my child well, I was
accused of child abuse. It haunts me and brings up all those suppressed emotions and
frustrations.

The fact that this caring parent had been accused of child abuse for evoking cries of "don’t hurt me
mommie" from her diabetic toddler during an insulin injection, only reinforced the pervasive nature of
diabetes on the lives of the child and her family, and contributed to increased stress for the mother during
her ongoing struggle.

Another new problem associated with this phase of the parents’ experience was related to the
variable of time since diagnosis for the child. The honeymoon, or remission phase of diabetes, often came
to an end for infants or toddlers six to twelve months following diagnosis. At this time the beta cells
cease insulin production and the child requires larger amounts of exogenous insulin. This is often given
in the form of a second injection before the evening meal. Although parents are taught about this
phenomenon, each hopes that their child will continue to produce some insulin and that a second injection
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can be avoided. However, generally due to cessation of insulin production combined with the physical growth of the child, an extra injection was usually required by the young child during this phase of the parents' experience. The fear and the mourning over the loss of the child's insulin production was combined with the frustration and anger over the need for a second injection and contributed a major source of stress for the parents.

One mother graphically expressed the stress and anger she experienced over the need to increase the insulin for her young daughter. Although this mother had acquired the ability to interpret blood sugar levels and rationalize the need for her toddler to start on a second injection, this rationalization did not reduce her anxiety level. Not only did the mother's perception of the situation cause her stress, but anticipated conflict between her young daughter and herself, and anticipated conflict between her husband and herself due to differing values and expectations, also evoked extreme anxiety. The mother explained.

M: I think she is getting ready for a second shot, and I don't want to go to that. It's a major source of stress to me, whereas 'A' [dad] says if it has to be it has to be ... but then he doesn't have to give it.

R: So this is a very anxious time for you because of the possible changes in injection schedules?

M: Oh yes! I do understand what's happening, and I do know she's growing and her life is changing too. It's not that I don't understand, I know when the sugars are high at night and in the morning and I can't control it with diet that the only thing to change is the insulin, but understanding doesn't always help, it doesn't take away all the stress ... and 'A' [dad], he'll never understand my stress.

Not only did the need for a second injection cause stress because of the physical struggle of giving the second injection, it also had connotations for the socialization of the family.

During this phase of the experience parents had often begun the process of building support systems. They had begun the task of teaching and described an increasing but guarded trust in others. Now, due to the threat of a second injection for their child, they were suddenly faced with the possibility of once again losing their support systems. Grandparents who had become more accepting of their grandchild's diabetes, and felt confident enough to care for the infant or toddler over a mealtime, would
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once again be excluded from the caretaking role unless they could learn to given insulin. Most grandparents had eventually accepted the responsibility of doing blood tests, but none felt confident enough to give insulin injections. A young mother explained how her own mother had just become comfortable with babysitting and that, consequently, she and her husband could often have supper out together. The threat of a second injection (which the grandmother could not give) had major implications for these parents and would once again change their lifestyle dramatically.

M: If it comes down to a second injection in the evening I will be so discouraged really. Another change that recently happened is the fact that my mother has just become comfortable doing blood tests and so we can leave 'G' with her for supper and go out a bit, but my mom still can't do insulin and I don't blame her with all the kicking and fussing that goes on ... so once again this insulin will take over our lives twice a day. It's a strain on our lives ... we have to rush home at 5 pm to do another injection, you see, at the moment if we go to the park we can get home at ten past five and still each supper at 5:30, but now with two injections we'd have to be here at 5 pm every single day and it really will change our lives again.

Parents explained how the insulin would once again control their lives. Many families who had begun to trust others and who enjoyed the freedom of leaving their infant or toddler with grandparents would have to reorganize their time again to accommodate the second injection.

The need for a second injection also led to friction and conflicts in families, conflicts between parents and conflicts between parent and child. These conflicts were perceived as stressors by parents. As one mother explained.

M: Well, I am just dreading it, the fight and the struggle twice a day instead of once. It's totally exhausting.

R: Can you get any support and help with the injections?

M: Well hopefully if it comes to that, my husband will be able to get home and he'll do it or at least he'll hold her while I do it, but of course it really messes things up if we want to go out at that time ...

Also for 'A' [dad] to be home every day at 5 pm will put a strain on him.

You see we argue about it all the time. 'S' [toddler] is better with her dad with injections, they play a game and I hold her and he does it, and he can't understand why I have such a struggle on my own, why I'm so afraid of a second injection. But we'll get over it because
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we have to, like we got over the initial stress, then we got over the stress of bringing her home, we’ll get over this too.

Although giving an extra injection caused stress for some parents, there was also a deeper understanding of why this had to be, and the need to cope with the situation.

Conflicts over diabetic control

Stress was also experienced in the form of conflicts between parents concerning their child’s general diabetic control and management. Parents described conflicting values and beliefs as well as differences in understanding of their child’s condition which led to different approaches in the child’s care.

A major source of friction between parents was their interpretation and acceptance of blood glucose levels.

One father was extremely concerned about long-term complications due to hyperglycemia for his child. Consequently, he preferred to see low blood sugar readings. However, the mother was constantly fearful of hypoglycemia and could not accept her husband’s approach to keeping their two-year-old’s blood sugar levels so low. The mother described the conflict this way.

M: You see with ‘B’ [dad] and I, we still have problems because of our different approaches. He thinks low blood sugars are better, he’s happy when he sees a 3 (mmol/L). Being in the health care field, his main concern is long-term complications, and he thinks 3 is good. Now even at the clinic, they say 3 is too low, but ‘B’ [dad] doesn’t go with us to clinic much and so we argue about that. I’m horrified when I see a reading of 3. I know it’s low normal if you don’t have diabetes but in ‘S’ [toddler] he can be running around as happy as could be with a reading of 3, then suddenly crash, and I worry about cognitive development if he’s always low. You see I’m a teacher, I’ve seen kids with learning problems, and I’ve read that constant low blood sugar levels can contribute to these problems … so I’m scared.

Varying degrees of worry and interpretation led to conflicts and tension between parents. This often resulted in friction that was difficult to resolve.

Issues related to food

Issues and concerns over food continued to be a major stressor for families during this phase of their experience. However, parents had a different way of approaching the situation. In one family, the young child (who was an infant when diagnosed with diabetes) had learned to manipulate his parents.

He had matured cognitively and was beginning to understand the significance of food and the attention
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his refusal of food provoked. His parents acknowledged that he could ‘fake’ being ill, and had learned how to vomit his food in order to gain his parents’ attention. The parents described the differences in their approach to this problem. Because they were a little more relaxed and more aware of the timeframe they could work in before absolute panic ensured, these parents were able to send their child to his room for a brief period before knowing they had to feed him again to prevent hypoglycemia. The mother acknowledged that, had the vomiting started a year ago, they would have been totally out of their minds and unable to cope or to know what to do. However, the father also explained that this probably would not have happened a year ago because their son was only a baby then and not smart enough to be manipulative. Consequently, once again, parents identified the significance of the timeframe in relation to their own ability to handle the situation, while at the same time acknowledging that certain events in their experience occurred because of the passage of time and the maturation of their child. The parents’ accounts vividly describe this experience.

M: He’s a little beggar. Sometimes he’s genuinely ill and he lies on the floor moaning, he’s quite the little actor. Other times if he doesn’t like something, he can fake being ill. You see, he has some favourite little blankets that he likes in his crib and if we don’t given him the right one, he will just sometimes throw up. He’s learned how to literally throw up.

D: He does it on purpose you know! He actually tells me that he’s going to throw up. Sometimes I’ve just taken two hours carefully feeding him to prevent his blood sugars going low and he tells me he’s going to throw up and he just does. Then you have to start feeding him all over again and it’s frustrating. He knows it panics us, he does it for attention.

M: Yes, he can just throw up. For a couple of months now if there is something he doesn’t like, he will just tell me he’s going to throw up and he does. I’ll talk to him quite sharply and say "no you don’t", but he just stands there and up it comes, all over the place.

D: I think it’s for attention ... if he doesn’t want something, this is his way of telling us "no way, I don’t want this". But of course he’s learned the significance of food for him, he knows we both get so tense if he doesn’t eat and food is an issue, it really concerns us!

R: So food can become an issue of control for you?

M: Well, a year ago it would have been much worse, we would have been totally out of our minds if he had done this. Now, we are a little more relaxed, what we say now is, "fine, if you are not going to eat then go away", and he’s put to sit in his room. We watch to be sure he doesn’t go low but then, usually after a while he’ll come out and eat something he likes.
Despite their ability to understand and to deal with this situation more logically and with less panic, the parents also identified confrontations over food as being an ongoing issue or stressor that constantly concerned them. Generally the child won out by receiving a substitution of food that they liked, and parents questioned whether the constant emphasis on food would lead to major eating disorders or bad eating habits in the future. Other families shared this concern.

M: It's an issue that could get bigger over time ... this issue over food ... We handle it all better ... if he won't eat we just cut back on the insulin ... but food is such a constant focus it's hard for a two-year-old not to take advantage.

For a parent whose young child had initially been too young to recognize or even ask for different foods the situation changed, and the mother was faced with the dilemma of a child who wanted to try different tastes.

M: Well, things have changed there. You know she used to just be happy with her cucumbers or crackers and always brought the cake to me? Well, now it's different. If someone is eating something else, she wants a taste. Like her little friends when they have a treat and want to share, she says "oh mommie, what is that, I want it", but as she gets a little bigger and out of my control and goes to playschool and so on, then I can see her trying things because she's really too young to know right from wrong.

Another mother explained.

M: We've run into another problem ... he can open the fridge and he gets up in the night to get juice ... he says he's low ... but usually he's not, he just wants juice ... but he knows juice is for lows so he's very smart, he says "me low" even though he has no idea what that means.

The constant fear of hypoglycemia remained on a continuum from phase two of the parents' experience into phase three, and will not be presented again in detail. Even as the child got older the fear of hypoglycemia never subsided. Some parents did explain that they experienced intense panic if their toddler indicated they were feeling low. However, although the toddler was right on rare occasions, in most instances they were wrong. Because "feeling low" was associated with receiving juice or sweet foods, many toddlers tried to express their desire for these good-tasting foods by saying they were low.
Behavioral issues

During this phase of the parents' experience the infants or toddlers had matured. They were beginning to assert their newly developed abilities and their desire to be independent. Although developmentally this was a forward step for the young child with diabetes it could result in behaviours that caused added stresses and problems for parents. Sometimes toddlers insisted on helping with the techniques of blood glucose monitoring or insulin injections, yet had little ability to handle these techniques correctly. One mother explained.

M: 'T' wants to do everything. He's very independent, very aggressive, but he often spoils a test because he pushes buttons on the machine at the wrong time ... sometimes it's very frustrating. We try to involve him but it can be a problem. He screams if he cannot help.

Another mother described behavioral changes that had occurred due to her young daughter's development.

M: Well, it's funny how things have been going lately. With the insulin, 'S' is still fighting. I think it's partly being two as well, partly wanting to be in control herself. Now the finger pokes are much better, no problem except she wants to choose the finger, wants to push all the buttons, and actually that was easier when she was little because she didn't interfere. Now she has to choose the finger and gets angry if she can't. She also likes to do injections to us, not to herself, but to us or her toys.

Some parents described exaggerated behaviours or responses in their toddlers that appeared out of context and not related to the child's diabetes. One mother explained her young child's reaction to a simple procedure, such as applying cream to a rash.

M: We've had another problem lately. You see she does have this thrush infection, and putting the cream on she just kicks and screams and I can't get near her to put it on. It's really nothing to do with her injections, but she fights more over those too ... I feel so sorry for her, she's so little and it seems she struggles and fights every minute of every day. It causes us both a lot of stress.

A father explained a similar situation with removing a sliver from his young son's hand.

D: You'd think with all the injections and finger pokes a sliver would be no big deal ... I couldn't believe the fuss. For his blood test he holds his finger out. For the sliver he screamed hysterically. It's hard to fathom a two-year-old's behaviour.

These toddlers behaved hysterically for a relatively simple procedure, and parents had difficulty understanding or rationalizing their child's behaviour.
Despite the parents’ relief at seeing their infant or toddler grow normally, the achievement of developmental milestones could create confusion and stress for the parents. Because the young child with diabetes was the first child for parents in all but one family in the study, knowledge of child development and expected behaviours was limited. This continuing knowledge deficit created stress for the parents. Concerns for the child’s future added to the parents’ stress.

**Anticipatory worry**

As parents became more familiar with their young child’s needs they also began to anticipate the future and to worry about events that could happen, or situations that could arise, to threaten their child’s safety or survival. Much of this anticipatory worry was induced by the parents’ guarded ability to trust others, and their own feelings of responsibility for their child’s very existence and future well-being. Parents described feelings of panic in case their toddler should wander off and get lost. They expressed fear that a stranger would not know that the child had diabetes and would not recognize the symptoms of hypoglycemia. The anticipation of the young child entering playschool or kindergarten evoked similar feelings of panic. Parents feared that teachers or caregivers would not understand their child’s needs. These pervasive and difficult to subdue worries were identified as stressors across the majority of parents’ accounts.

The mother who expressed concern in case her child got lost described how threatening and frightening she thought diabetes could be. She was aware of her child’s vulnerability and total reliance on others for his survival. She explained her worry this way.

M: Well it’s something to be frightened about because I find it terrifying that ‘A’ s body is unable to produce something (insulin) that is so vital to life and survival. I have nightmares about incidents that may never happen but could happen, that scare me. For example, say if he got lost and he’s only little, he could wander off and get lost and he couldn’t tell anyone he was diabetic and needed food. He could go into an insulin shock and a coma and die and although he wears his medic alert bracelet, everyone doesn’t know what it means. Because he is totally reliant on someone else, I find it very frightening. What if he were abducted, what if we missed an insulin reaction? I live with that fear all the time ... I guess things will change eventually.
This mother cited hypoglycemia as being the major cause for her fear and worry. She also worried about her son’s inability to produce a vital hormone necessary for life.

Because three mothers in the study had either delivered or were expecting new babies during the course of this study, worry about leaving the diabetic toddler with others was an issue presented by many families. One mother expecting the birth of her second child worried in case she went into labour in the middle of the night and would have to leave her young diabetic daughter with neighbours. Although only six months pregnant this mother was already planning in anticipation, and described her fears associated with the event of her impending labour. She explained that worry about her young daughter’s welfare detracted from her pleasure about the newly-expected child. She explained.

M: I worry about going into labour in the middle of the night and needing to drop ‘G’ off somewhere. We do have neighbours, and as soon as we get to the hospital I can call my parents on the island and they will get here as soon as they can ... but that’s not soon enough. I visualize ‘G’ at my friend’s house and it’s morning and they don’t know to give her the insulin or what to feed her and she goes low with a seizure and I’m not there to help her. I’m giving birth to one child and neglecting another ... I’ve planned everything ... but even going into labour will be a nightmare ... so much to plan, so much to worry about ... you can’t even go into labour without the diabetes taking over.

Worrying about future events, in particular insulin administration and hypoglycemia for her child, was a reaction this mother described as being due to her stress and guilt about leaving her young diabetic child.

Anticipated worry about future events also prevented one young mother from taking her infant son and diabetic toddler to the park. The mother imagined incidents of trying to meet the needs of both her children at the same time, and being unable to do so. She described her fear of trying to help her toddler with diabetes during a hypoglycemic reaction and, at the same time, having to ignore her infant son. A recurring nightmare, during which her infant was abducted while she was meeting the needs of her diabetic youngster, served to discourage this mother from taking her children out together. She explained her fears of the anticipated events this way.

M: It must sound very silly but I live in constant fear of taking both children out together. It would be so good to put ‘A’ [infant] in the buggy and take ‘T’ [toddler with diabetes] to the park .. but I waken at night worrying. I have this nightmare. I see us out and I am holding
the baby, when ‘T’ has a reaction and I don’t know who to take care of. I put the baby down while I attend to ‘T’ but, while I’m busy, someone abducts the baby. It’s a horrifying dream... very bad, but it’s something that could happen so I stay at home.

Another source of worry for parents was the anticipation of their child starting school and entering kindergarten. Although the event was two or more years in the future, the parents feared leaving their child in the school situation. Parents explained how totally responsible they felt for their child’s welfare and future health. They dreaded the day when they would need to trust others implicitly with their young child’s care. Most parents cited episodes of hypoglycemia as the major concern for anticipated worry.

As one mother explained.

M: It almost seems ludicrous to worry about ‘Ch’ going to school already. He is so young and there is another two years to go, but I’m worrying and planning already. I visualize the first day. All I have to tell the teacher about looking for symptoms of low blood sugars. I imagine all the children, the teacher is busy and ‘Ch’ goes low and no one notices. Why I worry about it now I don’t know but, if I don’t have anything else to concern me, I worry about that.

A father explained.

D: We have taken such good care of him ... invested so much energy, so much heartache, so much time we can’t imagine him managing without us. His future is our future so of course we worry and plan, and plan and worry ... it’s a constant rollercoaster of emotions and anticipation.

Other parents described the time and effort they had invested in their child and how they feared the possibility of someone else destroying their work.

M: Well, we have protected him, nurtured him since he was five weeks old. We’ve been exhausted, depressed and totally stressed out ... but we have watched him grow. We’ve invested so much of ourselves in him, if anything went wrong we could never forgive ourselves.

Because of all the emotional and physical energy invested in their young diabetic children, parents had difficulty accepting the fact that anyone else could be so protective.

Concern for their diabetic child also impacted on the parents’ perceived ability to manage another child.
Decisions to have other children

The diagnosis of diabetes in an infant or toddler had definite but often very different implications for parents when they were making decisions about having other children. For some parents, the initial idea of having another child was to replace the less-than-perfect toddler who now had diabetes. For others, the plan was to provide company for their diabetic child. Some parents questioned their abilities to care for another infant even though they had decided to have a second child. Other parents had made a definite decision not to have more children based on the overwhelming stress of caring for a toddler with diabetes. One mother tearfully expressed regret about making this decision. In one family where the mother was already pregnant again, the second baby had been unplanned. However, both parents perceived other medical problems in the mother as having far more impact on their fears for the new baby than their two-year-old son’s diabetes. Although there was great variability in the parents’ perceptions of this situation, it was an issue and concern expressed by all families.

One mother had discussed her feelings and concerns prior to the taped interview but shared them again when encouraged to do so.

M: Oh! I never, ever wanted to share this with anyone because it sounded so strange, so awful, that I only told ‘S’ [dad] and now you. But when ‘Ch’ was so ill and irritable, I began to think he wasn’t perfect anymore and I wanted a perfect baby. Everyone wants a perfect child, so I wanted to get pregnant again really soon. I wanted to have another baby right away just to prove I could have a perfect baby. You see, as soon as I knew ‘Ch’ had diabetes I thought he wasn’t perfect anymore. I just didn’t understand the disease at all but now, of course, I see he can be a normal little boy and time has passed and this feeling has gone, and I feel better. Time has healed and I don’t feel I need another child now ... but trying to make that decision was very stressful.

Two families who had decided not to have other children explained their rationale. In each case the mother was older when she delivered the child who later developed diabetes. Both cited age as being a factor in their decision making. However, both these mothers also explained that their toddler’s diabetes had been the primary reason for their decision not to have another child. Each felt they could not cope with the demands of a new infant as well as their child with diabetes. The first mother explained.
M: To begin with, I think I’m too old. I’m 40 now and I think it’s too late and too risky. Also his birth, or at least my pregnancy was a problem. You see, I’d had some surgery including a D and C and didn’t know I was pregnant and as it turned out a couple of months later I discovered I was pregnant and had been pregnant at the time of the D and C. So you see he was a survivor; he is still a survivor. But if I had thought about another child, which I didn’t, I would have been afraid. I would be scared a second one would have diabetes. I know it doesn’t happen very often, but the thought that I could have two like that would be too much for me to handle.

The second mother described her fears and concerns in a somewhat contradictory manner. She first said she could not have managed another child because of her son’s diabetes; then later she regretted the decision not to have another child. This mother later described how therapeutic it had been for her to talk through her own contradictions and thoughts about her decision, because she had not been provided with such an opportunity before. She was not exactly sure how she felt about it, even when she had finished explaining.

R: Are there other things that impact on your life?

M: Well, maybe one of the most significant things that have greatly impacted on us was the decision not to have another baby. We were so busy and I was so exhausted and afraid, and we thought it might be too much for us to handle at our age. Now I’m beginning to regret that decision. Of course there is no guarantee we would have had another child. I’m 43 now and ‘G’ [dad] is over 50. But soon after ‘A’ was diagnosed we were so stressed we could hardly manage him and all the other things happening in our lives. I was afraid we’d have another child with diabetes like my brother has. Anyway, it wasn’t really the fear of another child having diabetes, I just think we were so tired and so overwrought, we decided one child was enough. But I think I regret it. Now I think I’ve missed it, I’m too old at 43. It would have been nice to have two. But actually I was very, very stressed and with diabetes, it’s like having two toddlers anyway ... all the extra work.

Although her explanation had been contradictory, this mother had expressed regret about her decision not to have another child. Conversely, two mothers who had planned pregnancies after the diagnosis of diabetes in their first child, later regretted the decision. One mother, who was pregnant with her second child during the course of the study, described a wish to go back, to not be pregnant anymore, because she didn’t know how she could possibly give enough love and care to the new infant when her diabetic toddler required all her love and attention. This mother explained that she had grave concerns about her ability to parent a second child.
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M: We really wanted another child, a companion for ‘G’ but, I got pregnant again so quickly, I didn’t have time to change my mind. Now I feel so bad and so depressed I think I need counselling. I don’t know how I’ll cope. ‘G’ takes all my energy, needs all my love. I don’t know how I can love another child. I feel so sorry for this unborn baby because I don’t want it any more. I wish I could go back and not be pregnant ... you see caring for ‘G’ is already like caring for 1½ or 2 children. What if the baby cries and needs feeding when ‘G’ needs her insulin or goes hypoglycemic ... how can I handle both? I question my ability to cope ... and what if our second baby got diabetes? I’m very anxious.

The second mother who shared similar sentiments had a two-week-old infant when the study began. The parents’ older son had been diagnosed with diabetes at five weeks of age. The mother explained that throughout her pregnancy she had been in emotional turmoil, regretting the fact that she had become pregnant and worrying about her ability to share love and attention between two children. She explained.

M: When I became pregnant I wanted to change my mind. I was terrified about having another baby. Taking care of ‘T’ [infant with diabetes] was already like caring for 2 children, ‘T’ plus ‘diabetes’ ... I also asked myself, what if the new baby has diabetes? However, although I was fearful of our second child having diabetes too, I was more fearful of not coping. I asked myself how could I manage all “T’s needs, plus a new baby; diabetes is so demanding ... how could I share my love and my energy?

The father took up the conversation.

D: Yes, we already realized that it would be difficult to bring up a normal toddler as well as a toddler with diabetes ... You see we consider ‘T’ is our miracle since he was so tiny when he got diabetes, and we have invested our whole lives in his life ... no one really knows the effort and heartache we’ve put into ‘T’ and still will have to for many years to come.

In each of these families the decision to have another child had been weighed against the demands of caring for their infant or toddler with diabetes. Whether parents had decided not to have another child, or had planned another pregnancy, diabetes had impacted on their decision making process and had created emotional turmoil. The stress of caring for an infant or toddler with diabetes had resulted in contradictory feelings or ambivalence in the parents’ decision making about having other children.

Some justification was found for the parents’ concerns and apprehensions when considering the problems faced by the parents who delivered their second child during the course of the interview process for this study. The mother was extremely ill for many weeks, post-delivery. During this time emphasis
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on the toddler's diabetic management regimen was diminished. As a result the toddler's diabetes became
totally out of control. The father reported.

D: ‘V’ [mother] was so ill she almost bled to death. Her illness took precedence over ‘S’s
[toddler] diabetes. Consequently ‘S’s diabetes is totally out of control ... his insulin is all
wrong ... it’s because he hasn’t received our undivided attention. The baby is so wonderful,
we all love her, but her arrival has put unimaginable stress on our lives.

Because this mother’s pregnancy was not planned the family had not been faced with the decision of
whether or not to have a second child. However, diminished parental attention had resulted in loss of
diabetic control for the toddler. This graphically illustrated the reliance these young children had on their
parents, and that lack of attention due to any cause could result in a life-threatening situation for the
diabetic child. This concern was recognized by parents who were given the option of planning for a
second child.

Although the parents had described themselves as moving into a much easier and much less
stressful phase of their experience, the foregoing accounts have identified several recurring or sustained
stressors as well as some new issues and concerns. The passage of time and the infants’ or toddlers’
consequent growth and development created some relatively unique situations for the parents, and the
pervasive nature of diabetes and its required management continued to shape the parents' experiences and
evoke emotional responses.

Reactions and Emotional Responses to Perceived Stressors

Because the parents in this study continued to experience multiple and complex stressors in their
lives, their accounts also revealed a variety of emotional responses that were either sustained or recurring
from previous phases, or newly experienced at this time. Because of the intertwining of emotional
responses when presenting the parents’ perceived stressors, the following accounts will be a brief
summarization of the emotions and feelings experienced.
Recurring and sustained emotional responses

Although parents had vividly described moving into a new phase of adaptation and acceptance of their infant’s or toddler’s condition, and had described feeling more relaxed, more in control, and more comfortable with their situation, many emotional responses recurred or were sustained when new stressors or crises arose. These emotional responses were often experienced on a continuum from phase two of the parents’ experience. Although some emotional responses were described as less intense in some instances, others returned with previous intensity.

Parents did describe a return of sadness, depression, and grief when new problems arose. They also identified recurring and often sustained frustration, anger and anxiety over their constant struggles with injections. One mother whose daughter had been diagnosed for over a year described her emotions.

M: I know I shouldn’t really feel angry, or sad, or frustrated anymore. I should be over this by now but I’m not. I still feel angry and sad and frustrated, and each time I struggle over insulin the sadness and frustration and anger returns.

Another mother explained.

M: I still cry a lot. So often I’m crying inside even if I’m cheerful on the outside. I feel cruel when I poke this little child who doesn’t deserve it ... and, when she screams and asks "why are you hurting me, go away" ..., I know that some of that close mother/daughter relationship is lost forever and I grieve ... I know I can never get it back.

This grieving over the loss of a mother/child relationship or bonding appeared to increase during this phase of the experience. In contrast, a deeper bond seemed to develop between fathers and sons and, in some cases, between father and daughter. As one mother explained.

M: ‘B’ [dad] and ‘S’ seem to have a special bond. The diabetes has made ‘B’ more attentive. Father and son spend more time together. ‘B’ does much more for ‘S’ [toddler] than he would have. They do blood tests and injections together.

Another mother explained.

M: I think ‘S’ [dad] and ‘C’ [toddler] have a special affection and feeling for each other. You see ‘S’ does all the injections. They go off together, it’s a special time they have together.
The mothers of two toddlers explained how the fathers were much more accepting and competent over performing painful procedures, and that the young daughters responded more positively to their fathers.

M: ‘A’ [dad] seems to have this calm approach. ‘S’ behaves better for her dad. I think it’s because I am with her all day, I get so anxious and uptight and worried. ‘A’ is more pragmatic.

The second mother said.

M: ‘C’ [dad] is wonderful. He just takes over and manages ‘G’ [toddler]. I wish I had his patience.

For mothers, this appeared to be a particularly difficult time, as struggling with fighting, kicking toddlers who could now protest more loudly evoked feelings of despair, as well as frustration and physical and emotional exhaustion. For a parent who was accused of child abuse, the feeling was one of total devastation and self-doubt. Suppressed emotions of fear and guilt and feeling out of control returned, and anxiety about her own ability to cope arose.

As the honeymoon phase of diabetes came to an end, parents mourned their young child’s loss of insulin production, and recurring anger and frustration was experienced. Some of the freedom gained by parents during the time their young child was on one injection of insulin was suddenly snatched away due to the need for an evening injection. This stress left parents feeling discouraged and resulted in the trauma of conflict and dissatisfaction.

Fear of hypoglycemia remained constant for the parents, although the intense fear and anxiety experienced when their child vomited or would not eat was diminished. Knowledge and understanding of what to do in such circumstances reduced fear for the parents. However, concerns about future eating disorders for their children increased.

Two major stressors for parents that evoked intense emotional responses were those of anticipatory worry about their child’s future, and decision-making with regard to having more children.

However, regardless of the articulated concerns and anxieties, all the families did acknowledge having times when they forgot about their child’s diabetes for brief, fleeting moments, and laughed and
had fun. The overriding and pervasive fear of hypoglycemia seemed to be the emotional response that remained constant and did not dissipate even in a family where the toddler had been diagnosed for over two years.

From the parents’ articulated accounts it appeared that many of the parents’ anxieties and fears were reflected in their deep commitment to guarding their child’s health and protecting their future survival. Coping strategies employed to ensure this survival will be presented from the parents’ accounts.

Coping Strategies Employed by Parents to Manage the Situation

During this phase of the experience, parents began the active process of taking control and adapting to the sudden, unanticipated event of their child’s diabetes. The families began to regroup, to achieve some semblance of order and power, and to meet the challenge of many stressors and recurring crises impacting on their lives. Parents’ attitudes towards their child’s diabetes changed. They began to relax and to have confidence in their own ability to cope. These changes in attitude resulted in modification of goals related to managing the child’s condition. New problems, frustrations, fears and conflicts arose, which called for new coping strategies, and continuing struggles were often compounded by developmental issues in the child. These struggles and issues often required changes in strategies that had previously been used by the parents. However, strategies perceived as vital to the child’s well-being and future development were retained. Overall, the parents’ ultimate commitment was to ensure that their infant or toddler with diabetes survived and was competently cared for. To this end, the parents utilized coping strategies such as taking charge, being flexible, maintaining vigilance, trusting others, building supports, growing as a family, managing stress and worry, sharing; talking (hidden benefits of study), comparing with alternatives, and accepting their child’s condition.
Taking charge

Parents described the necessity of caring for their child as competently as possible. This involved taking charge, gaining confidence in their own ability, making decisions, and being positive over the long term. Despite the new problems that arose, parents described a need to get on with their lives, to accept the required management for their child, and to incorporate this into a more normal family life. One parent explained:

D: We have really got to learn to live with this [diabetes]. It won’t go away, so we’ve got to manage it until he’s a little older and able to take over some responsibility himself.

M: (laughing) Sure, I figure we’ve got at least 20 years to go before our part of the struggle’s over, and ‘T’ is in charge.

Another family described the task of learning to live again, as opposed to just surviving, as they had during the early months following their child’s diagnosis. The mother explained:

M: Well, in the beginning, you couldn’t call it living, or even managing, really ... it was hour by hour survival tactics. Now we realize that we can’t go on living like that. We have got to take charge. We have got to put our lives together. So we are beginning to think about ourselves a bit, about our needs as well as ‘G’ s.

Beginning to live again involved understanding their infant’s or toddler’s needs, and understanding their own needs. One family described taking up to a year to get used to their diabetic child and to recognize what interventions helped the child to feel good or bad. As the mother explained:

M: It took us almost a year to get used to him and to know what he needed and what made him feel good and what made him feel bad. It took so long to get used to this, we thought he’d never be a normal little boy again. We were all so stressed out, it was so hard and I often wondered how I could manage if it didn’t get better. But now I understand and I can help him, and things are much better.

Recognizing their own progress and understanding their child’s needs was based on increased knowledge of the child’s condition and the required management regimen. Parents also described gaining confidence in their own abilities as being a major step in the process of taking control and feeling more relaxed. A father explained:
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D: I feel so much more confident now. If I see a low blood sugar I'd reduce the insulin, or I wouldn't give any insulin at all if I thought 'R' wouldn't eat for me ... So it's totally different now.

Parents described much of their increased self-confidence as arising from a clearer understanding of how the insulin and food worked for their child. This understanding facilitated the parents' ability to make adjustments in the insulin dosage or diet if required.

M: I'm in charge now ... you see, I even understand what kinds of food affect 'S's blood sugar levels. I know that after pasta she goes low, not high, so she can eat more pasta than other foods. Also, if she has pasta for supper I give her extra milk before bed, to stop her going low during the night ... It's a good feeling to understand these things and to have a little control.

This ability to predict the effects of insulin and food on their child's blood sugar levels provided parents with feelings of empowerment and comfort. It contributed to their self-esteem and made them realize that they had the ability to make a difference in their child's diabetic control. One mother described feelings of satisfaction that she could manipulate both insulin and diet in order to control the situation and help her child.

M: I think 'A's control has been much better lately. My cooking isn't nearly as fancy. I don't use butter and oils as much. Also, although I don't fully understand all the permutations of the insulin, I do change the long and short insulin a bit, according to his blood sugars. So if I see a very high sugar before supper, I will add a ½ a unit of short-acting insulin to his long. If he is low in the morning, I reduce a ½ unit of insulin, and I feel comfortable with that now. It has instant results, so I feel satisfied that my science is working for me.

R: So this ability gives you a bit of control over the situation?

M: Oh yes! It gives me power and control to see it working so that when we do travel and move, I'll know what I'm doing.

This family was planning a move that involved considerable travel, and it was important for the parents to feel confident enough to handle their young son's situation independently.

Other families described the ability to relax and to feel comfortable with their decisions as contributing factors in the adaptation process. Parents explained this way:

M: Well, I think we are less tense, I think we are easier-going in watching her blood glucose numbers, and if it is lower, I'll give her more food, or if it is high, I feel comfortable to take
a bit of food away. I also feel able to change her bedtime snack. We feel able to adjust things ourselves more now, which we would never have done before, so that’s a change.

D: Our knowledge and understanding has also increased dramatically.

One mother who had been unable to relax or to deviate from the imposed regimen in any way during the first few months of her daughter’s diabetes explained changes that she had incorporated into the family’s lifestyle.

M: Well, with regard to the food, we are learning to relax and things have changed considerably. Now we give her a bit of gum, and this is different. It’s a whole new level and we are trying to be a little bit different ... we are getting a bit more lenient or experimental. So we’ll try a scone or roll instead of arrowroot cookies, and when we are out we’ll try restaurant food.

An ability to relax more, to experiment a little and become more lenient in their approach to their child’s diabetes led parents towards describing the next coping strategy.

Being flexible

During the early months of the parents’ experience, flexibility was not perceived as an option. In fact, being totally riveted or bound to the essential elements of the daily management regimen was deemed imperative by parents in order to ensure the well-being and health of their child. However, during this third phase of their experience, parents had learned how to be more flexible, more adapting, and more able to make suitable substitutions, particularly with regard to their infant’s or toddler’s diet. Some parents had adapted by making changes in their own values and beliefs about food and eating patterns. Although they were not entirely satisfied with the predicted long-term outcome of these changes for their child, it did solve the immediate problems of major confrontations over food. One mother described her child’s food preferences and her own ability to adapt this way.

M: Generally he’s a pretty good eater and likes most things, but sometimes he wakes up and wants mushroom soup for breakfast. So I say, “Why not? Why not mushroom soup for breakfast?”, and that’s fine. Just as long as he eats, I don’t care what he eats as long as he eats.

Feeding her child soup for breakfast met the toddler’s need for some control over the food he ate, while at the same time eliminating the parents’ anxiety about hypoglycemia due to the child’s refusal to eat.
Other parents, who had described the extremely stressful experience of trying to get their child to eat initially, had adopted a more lenient approach to their child's eating. The father explained:

D: Well ... he’s still fussy but now I don’t worry. If he wants Rice Crispies and milk for supper, he gets Rice Crispies and milk, I don’t care as long as he eats. Whereas in the beginning, I used to worry about what was proper, and the stress if he wouldn’t eat what I wanted him to eat was overwhelming.

Another parent identified a concern about the child's eating behaviours. However, this parent had consulted with health-care professionals and understood that toddlers could safely lack variety in food as long as the value of food substitutions was understood. The mother explained:

M: The dietitian explained to me that sometimes toddlers go on "food jags" and will only eat one type of food. She also told me that as long as the food contains the same amount of starch and protein or fat required it doesn’t really matter how ‘G’ gets it ... So once I understood that arrowroot cookies and peanut butter were as good as meat and potatoes for ‘G’, I could relax a bit. I wasn’t completely comfortable with this ... I was raised on meat and potatoes ... but I have learned to accept it and this certainly makes life easier. If she prefers cookies and peanut butter, that’s what she gets.

For these parents, achieving flexibility meant accepting their child’s preference for non-traditional eating behaviours, and considering nutritional value rather than variety of food. In contrast, some toddlers who had previously accepted lack of variety in their diet now suddenly developed the ability to recognize and desire the different foods available. Parents of these toddlers applied flexibility in a different way to accommodate their child’s needs. A mother explained:

M: When she was diagnosed, she was so little she just ate whatever I gave her. I never encouraged or allowed ‘S’ to taste restricted foods ... Now it’s different. I’m far more relaxed and knowledgeable and can allow her tastes without feeling absolutely guilty ... ‘S’ is now aware of all the different foods available and, if she asks for a taste, I can let her have one.

This acceptance of restricted food was also a coping strategy employed by parents to deal with the issue of birthday parties. Parents who had previously felt incapable of competently handling a party situation explained their current attitude:

M: A few months ago I would panic if we were invited to a birthday party. I’d spend days worrying about the cake, the ice cream, the goodies. I’d think it was easier not to go, to avoid the hassle ... Now I think ... well, it’s a party, if the blood sugar gets too high, we take him for an extra activity and bring it down again.
Another mother explained her ability to occasionally accept some deviation from the prescribed diet for her child, although this flexibility was limited.

M: I can manipulate things now, so I’m much less anxious. I can accept flexibility on certain occasions. You see, I now have the ability to analyze the situation. I can tell by the blood sugars what I can let her have and what I can’t, so it’s a whole new ball game really.

Despite the parents’ new-found flexibility, they still based their decision-making on the child’s blood glucose levels. Consequently, the need to adhere to a rigorous blood testing regimen remained part of the vigilance described by the parents as essential for their child’s well-being.

Maintaining vigilance

Although the parents had gained confidence in their own abilities to make decisions and to achieve some flexibility in their child’s regimen, most of the decision-making process was based on knowledge gained from methodically recorded blood sugar levels. Consequently, maintaining vigilance with regard to blood testing was part of the diabetic management that parents strictly adhered to. As one parent explained:

D: We remain totally vigilant with regard to blood testing ... four times a day before meals ... we never miss a blood test, it’s our lifeline, our window to viewing what’s going on inside our child ... our guideline to understanding ‘G’s needs, her moods ... and our ability to be flexible.

Another family explained:

M: We never go anywhere without the blood glucose monitor ... wherever we go, it goes too. To the park, the beach, the shopping mall. We never miss a blood test ... it’s part of the routine now, something we could never manage without.

For one family who were expecting their second child, one of the priorities that would have to be set was their toddler’s blood sugar testing. The mother explained how she had already visually incorporated this procedure into her new regimen when the second child arrived.

M: I worry so much about how I can cope with two children, but I’m not worried about ‘G’s blood tests. They can’t be missed, so I’ve got it all figured out ... you see, I’ll test ‘G’ every time the baby wakens for a feed. I still test ‘G’ before I go to bed anyway, she doesn’t even waken, just holds out her finger ... so I’ll do a blood test, then feed the baby ... same in the morning, test ‘G’ then feed the baby. Whatever else gets missed I know the blood sugar tests can’t, they are the only way I know how to adjust food and insulin.
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One family who described themselves as being reasonably accepting of their son’s diabetes, and found it to be only an inconvenience on most days, still explained that testing their child’s blood remained an essential element of their day-to-day routine. The mother explained:

M: Sometimes we almost forget the diabetes. It’s just an inconvenience more than a problem, most days. Just an appendage to a very busy schedule. However, we never forget a blood test. Insulin and blood tests are the way we maintain ‘D’’s health and very life, so how could one ever forget that?

Insulin administration was another part of the management regimen that was diligently practiced. Despite the many new problems and struggles identified by parents during this phase of their experience regarding this procedure, no parent considered omitting an insulin dose for any reason. As one mother explained:

M: This is ‘A’’s life I’m injecting every day. It’s frightening to consider what a powerful position we hold in preserving our son’s life. I am methodical with measuring and always give the shots on time, no matter what.

Another parent who had daily confrontations with her young daughter over the injections never once considered the alternative of delaying the insulin. She explained that her incentive for coping was the child’s life.

M: I fear the bond between ‘S’ [toddler] and myself is broken forever, and I grieve over that. However, despite my anger and frustration I’d never leave out an injection ... never ... it’s her life! I wouldn’t put a cushion over her head and cut off her oxygen, likewise I’d never leave off her insulin ... I still remember your [researcher] telling me insulin is like oxygen, essential to life.

Despite the flexibility in the types or amounts of foods parents offered to their child, another type of vigilance maintained by parents was the planning of meal times in order to prevent hypoglycemia. However, parents also had the power, knowledge, confidence and ability to reduce or increase insulin doses for their child to accommodate eating patterns. Consequently, although meal times did not change, the types and amounts of food offered to children often did.

Overall, the parents described feeling more comfortable with their child’s regimen since they had learned to combine vigilance with flexibility. These abilities gave parents confidence to share their
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knowledge and explain their child’s condition to others. The ability to explain their child’s diabetes to others led parents to describe experiences that constitute the next theme or coping behaviour.

**Trusting others**

Trusting others with their diabetic child depended to a large extent on the amount of information and teaching parents had provided for relatives and babysitters. Some parents had acquired the confidence and ability to manipulate and experiment a little with diet and insulin guided by results of their infant’s or toddler’s blood sugar levels. Some parents even described an ability to adjust sugar intake for the child when treating mild hypoglycemia. However, despite confidence in their own abilities, parents did not expect other caregivers to attempt any such flexibility. The parents’ major concern when leaving their diabetic child with anyone else surrounded episodes of hypoglycemia. Parents discussed their continuing anxiety about leaving their young child. They wanted others to experience the same anxiety and vigilance as they did. When parents taught family or friends about their child’s diabetes, a major emphasis was placed on treating hypoglycemia. When explaining her method of selecting people with whom she felt comfortable enough to leave her toddler, one mother expressed concern about the enormity of the other person’s responsibility, and felt only those who could do blood tests and analyze the results should be trusted with her child’s care. She described her concerns this way:

M: I could only leave ‘S’ with someone who is very familiar with her diabetes. You see, quite often she’s very, very low. The glucometer says low, doesn’t even give us a number, and she’s still running around with no symptoms, and that’s frightening. All I can say is, thank goodness for glucometers. And we only leave her with people who can do blood sugar readings, and treat hypoglycemia.

R: Yes, I understand.

M: You see, if we see a low on the glucometer, we give her juice immediately, and we expect others to do the same. However, although we are beginning to understand the diabetes and what it does to ‘S’’s body, you can’t expect a babysitter or stranger to do this. Earlier, we were talking about trust; I don’t think it’s lack of trust anymore, like it was, but rather that we understand more and want others to understand too.

R: Yes, I understand, so what do you tell other people?
M: We just tell them simply, if her reading is low, or she is shaky, pale and irritable, give her juice, then crackers and cheese. We leave it all out. We don't worry how high she goes because we know we can take care of that when we get home. You cannot expect sitters to do more ... as long as 'S' doesn't go low, we feel alright.

This mother described the basic survival tactics she felt babysitters should know, and was prepared to deal with the consequences of overtreatment for her child later. Other parents similarly described their expectations of babysitters or extended family members who were trusted with the care of their diabetic child. Each parent described the need to provide information and education for other caregivers.

One mother explained her ability to trust others because she had taught them implicitly how to take care of her child. Several months following her young son's diagnosis, this mother had to return to work for financial reasons. She approached the daycare facility where her toddler had spent happy hours before his diabetes was diagnosed. She had outlined her son's needs in detail, and the daycare staff had been prepared to manage his care, including the testing of blood sugars. This mother expressed her confidence in these teachers to take care of her son, and even rationalized that possibly his diabetes was in better control at daycare than it was at home. She compared his regular routine and eating and exercise patterns at daycare with her own disorganized and erratic routine at home after a long day at work. She felt that when she picked up her son each evening, she was often irritable and tired, and he was often irritable and tired. That combination often led to more erratic blood sugar readings than the toddler experienced during the day. She rationalized her thoughts this way.

M: Well, he's a real endomorph, he's not light on his feet. In fact, I think he should be more active for his age, but he's a plodder and actually, you know, with his diabetes, that's why daycare is so good for him, really, because everything is so regimented; it's ideal for a child with diabetes. You see, every day they have a snack at 9:30, lunch at 11:30, and a snack at 3 or 3:30. They exercise in the morning, and a nap right after lunch, and nothing ever changes, so it's really ideal. In fact, it's weekends and holidays when he's home that everything gets out of control. So I often think he's better off at daycare.

... Of course, I had to take a lot of time teaching them how to take care of 'A's low blood sugars. One day they were taking them all out for a walk, and they were crossing the street, and he just collapsed. His legs just gave out under him. The play group teachers had to carry him and treat him and I'm very glad I had taught them what to do.
Of necessity this mother had been required to leave her child in someone else’s care. However, her ability to teach others had provided her with the necessary confidence to leave her son. The willingness of the other caretakers to learn and take on the responsibility eased this mother’s anxiety.

In a similar situation where the mother had to return to work, the anxiety was lessened for the parents by the person with whom they eventually were able to entrust their child. The mother described the traumatic experience of losing a babysitter who had cared for her toddler prior to his diagnosis. This babysitter was unwilling to take on responsibility for a child with diabetes. The mother explained her anxiety in searching for another sitter and the terror she felt about the prospects of leaving her child. Her fears were eventually quelled when she found someone that she could trust implicitly.

M: Well, eventually after eight months, they wouldn’t hold my job anymore, and we couldn’t survive without my salary. You see, meeting all the needs of a child with diabetes is very expensive.

So I asked the babysitter who had worked for me before. She said, "No way, sorry, I can’t handle this, you can’t bring him back anymore" and I realized what an impact this would have on our lives, forever ... and I knew I had to find daycare for him and that, if I didn’t, I couldn’t go back to work. Then there was the issue of leaving him ... to begin with, I couldn’t, I was terrified. How could I ever let him out of my sight again, who could I trust with him, could I indeed trust anyone ever again, or was I totally tied?

D: Then a miracle happened. We were lucky enough to find a lady with two small children who had diabetes herself and she offered to babysit for us. She understands more than we do about diabetes, she intrinsically knows what to do, she boosted our confidence and was happy to take him.

R: So you found someone you could trust?

D: Oh yes! I mean she understands so well that when he is there, his control is fabulous. She feeds him on time and knows exactly what to do if he goes too high or too low ... it’s when he comes home he goes out of control again.

R: So you feel comfortable leaving ‘R’ [toddler]?

M: Implicitly, I can leave him with no problem. In fact, she understands so much more than me that I think he’s maybe even safer there than at home.

By this phase of the experience, most parents were beginning to identify their own need to get out. However, it was not an easy task to find people who were willing to learn and to take responsibility for
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such a young child with diabetes. Not all families were as lucky in finding support, even if they were willing to teach and ready to trust others. The parents' accounts describe their ongoing struggle in the next theme presented.

Building supports

Many parents explained how time had healed and eased some of their fears, and some of the fears of extended family members. They described the process of teaching grandparents how to cope with the young diabetic child's needs, and explained how they themselves were learning to trust others, and utilize these resources. One mother explained her experience:

M: Well, in the beginning my mom was terrified. My dad died soon after 'S' [toddler] was diagnosed and, consequently, it was all too much for my mom to handle.

Well, my mom is fine now, and 'S' loves to go there and it's good for them both.

However, some extended family members had not adapted so well, and were still unable to do blood tests. These support systems were tentative at best, and often created ongoing stress for parents. One mother described her sister's reaction:

M: ... but my sister ... she still won't do blood tests. She's afraid of the responsibility. I don't think my sister will ever feel comfortable, and it's different personalities and we can never change that.

Because parents themselves are fearful of hypoglycemia, they are cognizant of the fears of others. Consequently, they realize that building support systems is not an easy challenge, but one that will constantly be fraught by the enormity of their child's needs. The mother explained:

M: I truly understand how my sister feels ... you see, I'm not sure whether I would have been willing to take over had it been someone else's child. I'd probably be afraid too.

Other parents tried to rationalize the actions of friends this way:

D: But you know, some of our very close friends still don't understand and still don't want to know. I think they don't want to know because if they did, we might ask them to take care of him and they are far too afraid of that.

M: Yes, there is that real fear element for those who don't understand. They say things like, "Is he still on insulin every day?", or "Is he better yet?", or "Oh! You still have to watch what
he eats?” and it’s as if they want to shut it out. They have no idea and cannot understand what we go through.

R: So it is difficult to ask these friends for support?

M: Oh yes. They would never take him ... mind you, I don’t blame them, they see the stress we are under sometimes.

D: Yes! so we hope to get a support group of babysitters going ourselves. Like all of us with toddlers taking care of each other’s children.

The parents’ understanding and rationalization of their friends’ or family members’ fears constituted a coping strategy that helped parents come to terms with a relative dearth of support systems during this phase of their experience. Parents still identified the need for empathy, understanding and support, and these needs were experienced on a continuum from phase two. However, the difference at this point in the parents’ accounts was their better understanding of the situation and their desire and strength to work at improving their situation. Parents described actively seeking support for themselves and their children in an attempt to promote growth for themselves and their child.

Growing as a family

For parents, the need to grow as individuals and grow as a family was accentuated during this phase of their experience. Families were just recovering from the initial shock and coping with their child’s diagnosis and care at home. They were moving away from a holding pattern of just surviving one day at a time to realize that life must go on, and indeed progress. One father explained:

D: I’m just recovering from that state of survival tactics only. I feel I must get out of that holding pattern and back to growing as an individual. I now need to worry about keeping my job, building my career ... I can’t stay in shock for ever...

Another parent shared the same sentiments, and explained how she had returned to work just two afternoons a week to bring some normality back to her life and to diffuse her former total concentration on her child’s diabetes.

M: I just knew I had to talk to someone else. My career had been on hold...I needed to think ... I needed to grow. I needed time for myself as well as for ‘Ch’ [toddler]. So I took my job
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back just two afternoons a week while ‘Ch’ was at playgroup. I know it helps me too ... it gives me a different perspective.

Most parents described the need to achieve growth in order to retain their sanity and to achieve maximum growth for their diabetic child. One father explained.

D: I know we must get our life back together. We need to grow as a family and as individuals. We need to let ‘A’ grow like a normal toddler.

The mother expanded on this coping strategy.

M: Yes ... I have enrolled ‘A’ in swimming, in playgroup, in all the toddler programs. We want to make things as normal as possible so that he doesn’t feel different to all the other children.

The mother of another toddler explained her strategies to help her young daughter grow as an individual.

M: I still think she’s backward a little. I think we’ve over protected her and concentrated too much on the diabetes ... so I am trying some behaviour modification, encouraging her to be independent and try new things. We are trying to de-emphasize the injections and painful things and concentrate on the positives.

Part of the struggle to grow appeared to be an attempt on the parents’ part to incorporate the infant’s or toddler’s diabetes regimen into a more normal lifestyle. Although the following accounts of parents could be considered under a theme termed normalizing, they are grouped with the parents’ explanation of growing as a family for the purpose of this study. One mother described her attempts to maintain normality for her child.

M: I want her to be like a normal child ... I don’t want her singled out ... I want her to be a child first and diabetic second ... her being just a child, just like all the other toddlers, is very important to me.

Another mother described her experience at another child’s birthday party when the hostess had attempted to provide different and appropriate food for the diabetic toddler. Instead of being grateful, the mother described how upset she became during this situation. She explained that she wanted her toddler to be normal like all the other children.

M: Well, I took ‘G’ to this party and the mother had gone to such extremes. She knew ‘G’ shouldn’t have sugar so had prepared her special treats. A really cute candy mouse made without sugar and a special cup cake ... Then, instead of being grateful, I was angry and I cried. I didn’t want ‘G’ to be singled out. I wanted her to be just like all the other children.
So I said she could have cake like everyone else ... The mother couldn't understand, she thought she'd done 'G' such a favour, and she had really ... but I thought 'G' will never grow up ... never have the chance to grow normally if she's always treated differently.

Another mother described her attempt to make a regular day seem as normal as any other family.

M: I try to make our day as normal as possible, but it really isn't easy with all the pokes, injections and meal plans. However hard we try it isn't quite the same as a normal family. Sometimes the goals of parents as articulated in their accounts seem paradoxical. For while attempting to achieve growth and normality for their child, parents were faced with the dilemma of sacrificing some of the vigilance required to maintain good diabetic control. The amount of flexibility the parents felt able to risk in order for their child to be just like every other toddler created stress because it often contradicted the parents' identified need for vigilance. Adjusting their own lifestyles and socialization patterns to meet their diabetic child's needs also appeared to be an impediment to the parents' growth. The families' continued struggle with this dichotomy created feelings of ambivalence. The different styles of worry and coping are identified in the following theme.

Managing stress and worry

One of the most difficult areas of coping for these parents was managing their own style of worry while at the same time recognizing and understanding their partner's style of managing stress. The interdependence of parents and their need to grow, as well as to adapt, led to explanations of different styles of worry that often resulted in misunderstandings and conflicts. An inability to identify or understand the other parent's feelings was often an impediment to coping and adapting. Parents described different types of worry. For example fathers worried about maintaining their jobs in order to support their family. Mothers worried about confrontations with their toddlers over injections or food. The constant worry of both parents over managing their child's diabetes and controlling blood sugar levels was complicated by differences in attitude and expectations of the parents. The ability to deal with these differences was a difficult task and not too successfully dealt with even during this third phase of the parents' experience. Parents described their difficulties this way.
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M: There is still a great deal of tension at times. Now, on a good day when everything is going well, it's no big deal, we think we've got this diabetes and our emotions under control.

D: But then on other days we have difficulty communicating our feelings. We often have the same fears but show them in different ways ... Sometimes the fear and worry comes out in arguments, misunderstandings and friction ... sharing the worry doesn't bring us closer, it drives us apart. Usually we just don't talk.

The parents then described a need to sit down and talk, to understand each other's concerns and each other's approaches, to listen to each other's fears. One family explained.

D: We are often so engrossed in our own thoughts, our own interpretations, that we haven't the ability to communicate. When we talk our conversation hinges on diabetes, but only the immediate problem, so we go round and round. What we need is to sit down and identify our concerns ... share our feelings with each other just like we are now ... You have no idea how revealing this has been for me just to listen to 'M' [mother] ... I didn't even know she felt this way.

Many of the parents described their inability to communicate as being a major stumbling block in their quest towards growth and totally adaptation. One of the hidden or unanticipated benefits of this study was revealed in the parents' accounts and will be presented as the next theme.

Sharing; talking (hidden benefit of study)

The interview process and participating in the study was described by most parents as being therapeutic and helpful to them. Some parents revealed how little they had known about the other's feelings and how lack of understanding had led to conflicts. Most described the interview process as being a revelation, an opportunity to understand each other and an opportunity to understand themselves.

Some of the following explanations provided by parents illustrate the benefits they derived just from being able to talk and share their perceptions. One mother explained.

M: (to the father). I had no idea you felt this way too. Oh! If only I'd known earlier, if only we had talked and shared like we have today ... I thought it was only me who worried, you seemed so calm. Now I know it hurts you too.

A father stated.

D: We never really talked before. We shut each other out, we couldn't share ... but today we made an effort to be together for your interview and it's been the best move we ever made. We've learned so much about each other.
A father shared some of his experiences with the methods used to help his young son better accept insulin injections. The mother had never been let into the secrets before and was unaware of her husband's approach.

D: Well, I let him put the needle into me first, then another into him and we both have a needle so we share, and he accepts that because his dad has it too.

M: I had no idea how you did it, I didn't know. I wondered why he made less fuss with you. There's so much I don't know, I guess I've been too busy to ask.

In another family the parent thanked the researcher for the opportunity to share her thoughts, and explained the benefits she had derived from the interview process.

M: I thank you for coming, for listening to me go on and on. It was good to get it off my chest. I feel so much better, you know what I mean and understand what we're going through. I'd like to meet some of the other parents and children in the study. So thank you so much for including us, it's been very good for me and I hope I've been a help.

Another mother explained how helpful she had found it to be given the opportunity to talk. She suggested that regular visits from a health care professional, who could just listen to the parents' concerns and answer questions, would be extremely beneficial to the parents' well-being.

M: You know, these visits are so helpful, so therapeutic. It's as much help to me as I hope it is to you. I wish we had someone who could make house calls on a regular basis. Just talking things through is so therapeutic and makes me feel better.

Another parent explained how little she had understood about the changes that had occurred in her relationship with her husband since their toddler’s diabetes was diagnosed. She expressed the opinion that just talking had helped to put everything into perspective.

M: I really have benefited from talking this over, I didn’t even realize there were any benefits to diabetes at all until I started talking about ‘G’ [dad] and me, our relationship. Talking really makes you think, and this has helped me put things in perspective.

Each parent in the study described the benefits of having someone listen to them. Being able to talk and share experiences was described by parents as being a coping behaviour that could reduce the stress and increase understanding of the other parent’s needs and concerns. Another coping behaviour used by parents was to compare their young child’s diabetes with diabetes in older children.
Comparing with alternatives

During their child's initial hospitalization following diagnosis, parents had compared their infant's or toddler's diabetes to other chronic life-long illnesses observed in other children. At that time parents had considered diabetes to be a favourable alternative to most other conditions. During this phase of their experience parents chose to compare their infant's or toddler's diabetes with managing diabetes in an older child or teenager. Once again parents considered caring for a younger child with diabetes as being a favourable alternative to caring for an older child with the same condition. Parents rationalized that it was easier to care for an infant or toddler because they were so accepting and far too young to understand or to have known anything different. Parents also described themselves as being in control whereas, with an older child, it was the child who was in control. Parents rationalized things this way.

M: Basically, I think it's easier to handle a little one. After all, they are too young to know any different. Because toddlers are so reliant on you as a parent ... you are in control and that's easier.

A father explained.

D: Two-year-olds are so accepting, so utterly reliant it makes it easier. They [toddler] are also smaller, you can hold them down if you have to ... whereas how do you get a teenager to take his insulin if he refuses?

A mother continued.

M: He was so young when he was diagnosed he will never remember life without diabetes ... whereas say a child of 10 or 12 years will always remember life before diabetes and will mourn the loss of so many things.

One of the parents' articulated concerns was that older children had already experienced life without diabetes and would have more difficulty accepting their condition. They were not sure how they would handle problems if an older child refused to give their insulin injection or perform a blood test, and they were grateful that their infant or toddler was so accepting and easy to control. A mother explained.

M: Well, if there is any consolation I'm pleased it happened now and not later. I've met parents who have older children with diabetes and they [parents] have major problems. Kids will not do blood tests, won't do their insulin ... the parents are frantic.
At least with ‘G’ I’m in control and we know she gets the very best of care. I don’t think I could handle an older child, let alone a teenager.

The matter of being in control was of paramount importance to most parents. Loss of control over their child’s life was perceived as being inconceivable. As one mother explained.

M: I often compare ‘T’ to older children with diabetes and I think I’ve got it so much easier than other parents. You see I figure an older child is in charge of their own destiny ... whereas I have the opportunity to guide ‘T’. I’m in charge and can influence his future.

The fact that a young child generally coped well and had the opportunity of growing up with diabetes instead of having to learn to cope with it later, appeared to be a source of comfort to these parents. A mother described her feelings this way.

M: Well ‘G’ is coping really well, better than me really. She doesn’t know what she’s missing yet, she hasn’t had a lot of experience with candy or chocolate, and no experience of life without diabetes. She will grow up with this as part of her life and it’s a consolation to me that she will not have known anything different.

The only advantage that parents could perceive in caring for an older child was the child’s ability to recognize and treat their hypoglycemic episodes. Most parents lived in anticipation of the day when some of the responsibility for hypoglycemia would be lifted from their shoulders. One father explained.

D: The only negative thing I can think of when comparing ‘D’s diabetes to the same condition in an older child is that ‘D’ can’t tell us when he feels low. Having to predict and anticipate low blood sugars all the time is totally draining ... Now an older child can recognize the symptoms and be taught how to take care of it. That is a great advantage for parents.

I look forward to the day when ‘D’ can take over some responsibility for his condition, but I know when that day comes we will be experiencing other problems, other headaches.

By this time in their experience, parents were beginning to anticipate the future and to consider some of the advantages as well as the disadvantages of their child growing up with diabetes. Many parents had abandoned the absolute hope of an early cure for their child’s condition, and instead were considering their child’s future realistically.
Accepting the realities of diabetes

During the first and second phases of their experience the parents of the young child with diabetes were sustained by the hope of an early cure for their child’s diabetes. Many parents had difficulty facing the reality of a life-long condition for their child, and many preferred to deny the possibility of coping for their child’s diabetes over the long-term. However, during the third phase of their experience many families had a greater understanding of their child’s condition and were able to face the possibility of coping with diabetes in their child throughout childhood and adolescence. Many looked forward to the time when their young child was old enough to accept some responsibility for his or her own condition. However, each realized and accepted a long-term commitment to their child in the future. As one mother explained.

M: I used to have such hope. I believed a cure was just around the corner, any day now in fact. It’s what kept me going and I needed that during those first difficult months. However, now I’m not so naive, I’m more realistic. I realize we have this long battle ahead and had better come to terms with that...

Parents were also realistic in their assessment of the future and anticipated more struggles and frustrations and fears. They did not see the future becoming any easier. They just saw other challenges and difficult problems ahead. One mother explained.

M: I go to the support group now. I try to learn from the other parents. I try to understand what the future might be like for ‘S’ [toddler with diabetes] and us [parents]. It’s not going to be easy ... I felt sure it had to get better, and some of it does but, after talking to other parents, I think the struggles will get worse.

D: Yes, we talked to a mom who has a daughter who is 12 years old. She’s been a diabetic since 3 years but that mom is still frustrated, and still fights with her daughter. So I don’t know, this diabetes ... it never goes away and each new transition brings its own frustrations. You just think you’ve got it and something else comes along.

Some parents still held onto a semblance of hope for a cure which was initiated by their child’s prolonged experience of the honeymoon or remission phase of diabetes. The mother explained.

M: As long as ‘Ch’ is still making insulin I have hope. Maybe they will come up with a way to preserve his own insulin production forever. I pray this could happen every day.
Other parents looked to the future with reality and planned strategies to ensure that their child’s life would be made as normal as possible. A father explained.

D: We see him now as a normal toddler, playing, running, singing. He has such a sense of humour ... I think that will see him through. So we have to accept whatever life brings for him. Maybe a cure, maybe not, but whatever it is we have to build the best and most normal life for him. We pray for a cure, but we must also be realistic and accept what the future brings.

Both hope and realism were coping strategies adopted by parents to help them accept their infant’s or toddler’s future. Parents also perceived themselves as essential elements in the experience. They saw themselves as assisting their child with the magnitude of this health problem, and were prepared to continue with a lifestyle that would ensure the best possible outcome for their child.

Summary

From the parents’ accounts, the third phase of their experience began when they had learned to relax a little and to have faith in their own ability to parent a diabetic child. During this phase, most parents had acquired the confidence and flexibility to begin to trust themselves and others. Increased knowledge and understanding of their child’s condition served to empower parents and enhance adaptation. Parents explained the transition into this phase as being related to time, and seeing their infant or toddler grow and develop despite the diabetes was a major factor that contributed towards the parents’ ability to adapt. However, developmental issues in the child were also perceived as a source of stress to many parents.

Although the parents had begun to adapt to their new life situation realistically, they still experienced new or recurring stressors that evoked feelings of frustration, anger, sadness, guilt, grief or mourning whenever a new crisis arose. The young child’s condition also led to new stresses in the form of anticipatory worry about future events, and the decision to have other children.
In general, parents acknowledged an ability to take charge, be more flexible, maintain vigilance, trust others, build supports, grow as a family, manage stress and conflict more effectively and accept their child's condition. The process of talking and sharing experiences during the study interviews opened up new channels of communication and understanding for the parents.

Summary

Findings of this study indicate that parents go through three distinct phases in their experience of caring for an infant or toddler under three years with insulin dependent diabetes. The first phase of the parents' experience involves the diagnosis of diabetes in the child and the subsequent hospitalization. The second phase spans six to seven months following the young child's diagnosis and involves the parents' initial task of caring for their diabetic child at home. The third phase involves the parents' experience of living with their young diabetic child over the long-term and incorporating the daily management into everyday life.

Throughout each phase of the experience parents encountered multiple stressors and struggles which evoked emotional responses and reactions. The parents also developed coping strategies to manage their child's regimen, to reduce stressors and to respond to emotional reactions and feeling states.

During the first phase of the experience the initial diagnosis; the child's hospitalization; painful intrusive procedures; lack of sleep; exhaustion; learning to manage the complex diabetic regimen; dealing with health care professionals; lack of privacy, and being totally overwhelmed by the situation were all stressors that resulted in struggles for the parents. Emotional responses included fear, anxiety, sadness, anger, grief, blaming each other and blaming themselves, guilt, pain, exhaustion, loss of control and feeling totally overwhelmed. Feelings of relief at the child's diagnosis were also described by some parents. Coping strategies employed to handle the situation involved identifying needs, looking for a cause, being assertive, managing the regimen, accepting the child's diagnosis, seeking support, considering
alternatives and clinging to hope. The ability to manage the child’s regimen was sustained by the parents’ realization that they had no choice in the matter. Parents also described an overwhelming desire to achieve an appropriate standard of competence that would ensure the provision of safe, effective care for their infant or toddler at home.

During the second phase of the parents’ experience, taking the child home; making necessary changes in lifestyle; multiple losses; the uncertainty and unpredictability of blood sugar levels; the fear of hyperglycemia and hypoglycemia; confrontations over food; struggles with giving injections; taking blood tests; and developmental issues for the child were all described as stressors resulting in struggles for the parents of the diabetic youngster. Emotional responses and reactions to the perceived stressors included an ongoing grieving process, sustained sadness, anxiety, frustration, fear, depression and feelings of being totally overwhelmed by the enormity and complexity of their child’s needs. Reactions included changes in roles, relationships and responsibilities for family members, and conflicts and friction resulted due to the multiple stressors encountered by parents. Coping strategies employed by parents to manage their situation included a commitment to being methodical, maintaining vigilance, making decisions, sharing responsibilities, interacting with health care professionals, trusting others, identifying their own needs, reducing stress, and maintaining hope.

An overwhelming fear of hypoglycemia and struggles over insulin injections were major stressors experienced by parents that were described on a continuum through both phase two and three of the parents’ experience. Increased knowledge and understanding of their young child’s condition, and the passage of time were major factors in initiating the progress of parents into the third and final phase identified from the study data.

During this third phase of their experience, parents described their movement toward a new level of confidence and adaptation. They described a distinct change in attitude toward their child’s diabetes, and compared their current level of knowledge and ability to earlier experiences at the time of their child’s
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...diagnosis, or during the early months of caring for their infant or toddler at home. They also identified the passage of time as a healer. Time had provided them with a better understanding of their child's condition and also allowed them the opportunity to see their young child grow and develop normally. However, stressors and ongoing struggles were identified by parents and these included issues related to the child's development, ongoing frustrations with insulin injections, continuing fear of hypoglycemia, conflicts due to differing expectations and values of parents, confrontations over food, and behavioral issues in the growing child. Parents also identified new stressors such as anticipatory worry, which involved the parents' concerns about future events that could threaten their child's safety and survival, and the impact of the young child's diabetes on their decision to have other children. Reactions and responses to these stressors included recurring or sustained emotional responses, such as frustration, anger, fear, sadness and depression.

While taking control of their situation and learning to adapt, parents incorporated the following coping strategies into their lifestyle. Taking charge, being flexible, maintaining vigilance, trusting others, building supports, growing as a family, managing stress and worry, sharing and talking (which was described as a hidden benefit of this study process), comparing with alternatives, and accepting the realities of their child's diabetes, were all activities undertaken by parents to ensure the best possible future outcome for their infant or toddler with diabetes.

Throughout the articulated experiences, parents perceived themselves as essential elements in the process of assisting their child with the magnitude and complexity of the unpredictable health problem. They perceived themselves as being responsible for their child's well-being, future development and very existence. In order to deal with the enormity of their task, parents deemed knowledge, understanding, support, empathy, trust and someone to listen to them as essential to their own and to their child's survival.
CHAPTER FIVE

Discussion of Findings

Introduction

The purpose of this chapter is to discuss the findings of the study in relation to other authors' published work on the topic. The literature reviewed in Chapter Two provided a general background for this study, whereas this chapter will provide a more in-depth exploration of literature specifically related to the phases, conceptual categories and themes developed from analysis of data from the parents' accounts.

Because of the limitations of published research on families caring for an infant or toddler with diabetes, this chapter will refer to more general literature pertaining to care of the chronically-ill child. Publications related to family stressors, parents' responses to these stressors, and the coping strategies employed by parents to deal with the situation, will be discussed as a means of helping to explain the findings of this study. It was not the intent of this study to develop rigorous theory regarding care of the young child with diabetes, but rather to explore and provide a deeper understanding of the experience from the parents' perspective. Consequently, the literature will be used to explain the findings presented in this study, and to locate the study within the context of related work.

Although the material will be organized in a manner similar to that presented in Chapter Four, emphasis will be placed on selected and specific aspects of the parents' experience. An introductory discussion on insulin-dependent diabetes mellitus in infants and toddlers will be presented. This will be followed by a discussion of selected literature that is supported or refuted by each of the three phases of the experience identified by the researcher from the parents' accounts. The data will also be related to common adaptive tasks facing parents of children with chronic conditions as outlined by Canam (1992).
In addition facets of the parents' experience that have not been identified in any of the literature reviewed by this researcher will be presented.

**Insulin Dependent Diabetes Mellitus**

**in Infants and Toddlers**

Findings of this study indicate that parents of infants and toddlers with diabetes experience inordinate amounts of stress exacerbated by the child's young age, and the demands and fears associated with the complexities of the daily management regimen. Many of the stressors and struggles identified by parents in this study also noted by Kushion, Salisbury, Seitz and Wilson (1991) in their article pertaining to issues in the care of infants and toddlers with insulin dependent diabetes mellitus. These authors describe insulin dependent diabetes mellitus (I.D.D.M.) as a complex metabolic disorder whose optimal management requires close cooperation between the child, the family and the health care team. They also suggest that infants and toddlers with I.D.D.M. present a particularly complex set of problems that include altered physiology, a diminished ability to communicate feelings and needs, inability to cooperate with the treatment regimen and, for the family, an increased sense of stress. Kushion and colleagues (1991) also report that increased family stress and altered psychodynamics seen in families with very young children with chronic illnesses is exacerbated for families with infants and toddlers with diabetes. This exacerbation results from management issues which include difficulty in achieving maximal metabolic control for the child and the lability of diet, exercise, emotions and overall lifestyles seen in this age group. In addition, fears and anxieties associated with insulin injections, and blood glucose testing, fear of hypoglycemic seizures, and financial worries due to the expenses incurred by the treatment requirements were significant. Parents also experienced stress due to changing relationships, changes in family interaction patterns, and loss of support systems due to baby-sitters or extended family members being reluctant to take on the responsibility of the day-to-day management and care of an infant or toddler with I.D.D.M. (p.108).
All of the above stressors identified by Kushion and colleagues (1991) were also identified as stressors and concerns by the parents in this study. Possible financial worries were mentioned to a lesser degree by the parents in the current study. This could be a reflection of the support these families receive from the Canadian Health Care System. This service provides financial coverage through pharmacare or extended medical benefits for expensive items such as insulin and reagent strips for blood glucose monitoring. Such financial assistance is not always available in the United States where the families described in the Kushion and colleagues’ article reside. Kushion and others (1991) concluded that managing an infant or toddler with diabetes requires a team approach of caring for both the young child and the family. The authors noted that, during this developmental period, young children are unable to communicate their own needs or feelings. Consequently, the daily stress of the diabetic management regimen increases the already high level of effort required by the parents of young children. The physiological differences of children with I.D.D.M. also place specific requirements on management plans, and parents required support, education, and psychosocial interventions from health care professionals in order to meet the varying needs of these very young children.

In their introduction to the family and childhood diabetes, researchers Lorenze and Wysocki (1991) discussed selected research papers focusing on the impact of I.D.D.M. on the family of the affected child. These researchers discussed the relationship between managing I.D.D.M. in children and the family as an instrument of care and socialization. They concluded that "few childhood diseases rival I.D.D.M. in terms of the high degree of family involvement required for day-to-day management" (p.262). LaGreca (1991) reiterated that I.D.D.M. is a challenging and complex disease to manage effectively, and that the demands of insulin injections, blood glucose monitoring and dietary and activity regimens have lifestyle implications that make this a disease requiring a high degree of parental involvement and dedication (p.269). LaGreca also suggested that during early childhood, parents are required to assume total responsibility for the young child’s diabetic management because such young children are unable to
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identify or respond to their own needs. These findings were based on a study in which the mothers of 121 children with diabetes completed the Diabetes Family Responsibility Questionnaire. The LaGreca findings were consistent with the findings of the current study in which parents articulated heightened anxiety levels due to the realization that they were totally responsible for their child’s health, well-being and very existence.

In their recent study conducted to determine what parents of children with diabetes worry about most, Vandagriff, Marrero, Ingersoll and Fineberg (1992) reported that chronic disease in children can be a significant source of daily stress and anxiety in parents, and that this is particularly true for the parents of children with I.D.D.M. Because diabetes requires that parents as well as their children should follow a very structured daily regimen, this routine serves as a continual reminder of the child’s condition, and of the acute health-threatening episodes that can occur at any time (p.299). In that study, parents of 93 children with I.D.D.M. completed a modified version of the Diabetic Quality of Life measure to evaluate diabetes specific worries. Results indicated that the younger the child, the greater the amount of parental stress and worry experienced. These worries included difficulties with maintaining good diabetic control, child development issues, activity levels and affective responses to painful procedures. These findings supported parental concerns and worries identified in the current study.

A study by Betschart (1988) similarly concluded that the stresses and demands of the daily diabetic management for any child can have a devastating effect on parental functioning and parent/child relationships. In that study parents of children with I.D.D.M. responded to specific questions related to diabetic management and individual ways of coping with the struggles and frustrations of daily life. Betschart’s results were supported by findings of other studies which reported on the extreme stress experienced by parents due to the demands of meeting the needs of a child with diabetes (Allen, Affleck, Tennen, McGrade & Ratzan, 1984; Etzwiler & Sines, 1962; Kovacs & Feinberg, 1982; Schafer, Glasgow, McCaul & Dreher, 1983). Similar findings emerged from the current study.
This review of the literature related to insulin dependent diabetes mellitus in infants and toddlers was presented in order to place the current study findings within the context of recent works that describe the high level of stress experienced by parents who are caring for young children with this complex condition. These findings show that the parents' perceptions reported by the families in the current study, are not dissimilar to those reported in studies of similar populations.

Three Distinct Phases of the Parents' Experience

From the articulated experiences of the parents in this current study it became apparent to the researcher that families go through three distinct phases in the process of managing an infant or toddler with diabetes. These phases are linked to events occurring in the parents' lives which are related to the young child's condition. The phases follow a timeframe described by all the families interviewed for this study. The first phase of the parents' experience began with the initial crisis related to the diagnosis of diabetes in their infants or toddler. This phase included the acute onset of diabetes, the child's admission to hospital, the hospital experience for parents, and the events surrounding learning how to manage the child's condition in the hospital setting. The second phase of the parents' experience began when the infant or toddler was discharged from hospital and the parents began the awesome and frightening task of caring from their young child at home. This phase spanned a period of six to seven months post-diagnosis and, for some families, lasted even longer. Phase three of the experience was related to the parents' process of adapting to their child's condition and incorporating the diabetic management regimen into a more normal daily lifestyle. During this phase, families explained how increased knowledge and understanding, and familiarity with their child’s needs, had boosted confidence, and empowered parents to take control and feel more capable of shaping their child’s destiny. Many families explained how time as well as knowledge healed. Seeing the infant or toddler grow and develop both physically and cognitively was perceived as a major factor that contributed to the parents’ ability to accept and deal with
their young child's condition. However, new as well as ongoing stressors and struggles were also encountered by parents at this time.

Several theoretical models depicting a progression through a sequence of stages which are time-bound have been described in the literature. These theoretical frameworks describe parental reactions to a child who has a chronic health problem (Clubb, 1991). A variety of models has been developed to explain the parents' responses to special needs in a child such as cognitive deficiencies, congenital defects and physical abnormalities. Most of these models identify emotional responses such as initial impact or shock, denial, grief, focusing and closure (Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; Fortier & Wanlass, 1984). The models all conclude with an acceptance stage or closure which signifies parental adjustment to the child's condition (Clubb, 1991). However, despite the common support for this approach, some researchers dispute the outcome of the time-bound model and, instead, accept the concept of chronic sorrow. Limited research is available regarding chronic sorrow, which is a phenomenon seen in parents of the child with special needs. Advocates of chronic sorrow dispute the parents' arrival at the closure stage. Instead, they view the parents' response to the tragic event of an impaired child as being manifested throughout the lifespan of the parent/child interaction (Clubb, 1991, p.462). Copley and Bodensteiner (1988) proposed an integrated model which embodies characteristics of both the time-bound framework and the chronic sorrow concept. These authors believe parents of children with chronic conditions move in a circular fashion through two phases. Phase one includes the initial impact, denial and grief. Phase two represents the parents' acknowledgement of their child's handicap and long-term consequences. Emotional turmoil exists in both phases. The emotional upheaval is more intense during Phase one, whereas in Phase two the emotional turmoil begins to fade but never disappears completely. This model was limited to parents of physically-disabled children. Other models such as that proposed by Wikler (1981) were based on studies involving cognitively impaired children.
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A more recent study conducted by Clements, Copeland and Loftus (1990) used grounded theory to examine critical times for families with a chronically-ill child. Parents of children with diabetes, cystic fibrosis, or cancer identified specific times in family life when disruption occurs. Findings indicated that family needs increased significantly during the initial impact of the illness and during an increase in physical symptoms over the long-term.

In their longitudinal study that followed mothers of newly-diagnosed insulin dependent diabetic children over a six-year period, Kovacs and colleagues (1991) assessed the psychological functioning and levels of maternal depression experienced over time. Self-report symptom inventories were used and analyzed. Findings indicated that mothers initially reacted to the diagnosis of diabetes in their child with mild depression and overall distress, but that these initial reactions subsided in about six to nine months. After the initial phase of adjustment, there were slight increments in maternal depressive symptoms over the duration of the child's illness. These authors also found that psychological distress, including symptoms of anxiety, somatization, anger, suspiciousness and dysphoria also increased with the duration of the child's diabetes. These findings, related specifically to children with diabetes, appear to incorporate certain aspects of both the time-bound models and the concept of chronic sorrow. The findings of Kovacs and colleagues (1991) related to mothers' initial reactions seem to be supported by the data in the current study. However, none of the infants and toddlers in this study have been diagnosed long enough for their parents' accounts to be related to the findings. After the initial period of adjustment Clubb (1991) suggests that more research into the type of model most suitable for parents with chronically-ill children is needed, and that more scientific validation is required for all the models and concepts currently described. Most of the literature also appears to involve the mothers' experience and the paternal role has not been sufficiently studied (Clubb, 1991, p.465).

The three phases outlined in this study were not based on any previously constructed theoretical model. Instead the phases appeared to fall naturally from the parents' articulated accounts as the researcher
analyzed and compiled the data. Because of the young age of the infants and toddlers in this study, and because of the relatively short time since diagnosis of diabetes in their child for these families, more research to validate the significance of the three identified phases is clearly needed. Although these three distinct phases clearly identify the magnitude of the stressors experienced by parents, and describe a multitude of emotional responses to these stressors, they also introduce the phenomenon of the parents’ experience of managing the complex diabetic regimen. Because few other chronic childhood conditions require such complex and pervading management in such young children, these phases of adaptation could be unique to this population.

**Phase One: The Diagnosis of Diabetes**

Most infants and toddlers are extremely ill when first diagnosed and admitted to hospital. Consequently, the experience of the diagnosis and hospitalization of a previously healthy child was described as extremely stressful for all parents in this study. Kushion and colleagues (1991) report that a majority of very young children with diabetes present with diabetic ketoacidosis and are often extremely ill or even comatose when admitted to hospital. These authors did not discuss specific stressors experienced by parents due to the acuity of the young child’s condition at diagnosis. However, the impact of the initial crisis period and the responses of parents to this crisis were described by several authors. For the purpose of this discussion the stressors and resultant struggles will be combined with the emotional responses and reactions of parents during this critical period of their experience.

**Perceived Stressors and Parents’ Responses to the Situation**

In the current study, the initial stress for the parents began with the impact of the diagnosis of diabetes in their child. For most parents this was a devastating and frightening experience.
Receiving the diagnosis

This was the first theme identified from the parents' accounts in the current study and most parents began their story here. This initial crisis experienced at the time the infant or toddler was diagnosed can be related to the impact stage described by Fortier and Wanlass (1984). These authors suggest that impact signifies the beginning of the crisis for the parents and usually occurs at the time of the child's diagnosis. Anxiety and family disorganization results since the event is beyond the parents' repertoire of coping skills. Clements and colleagues (1990) also identified the diagnosis of diabetes in a child as being a critical time experienced by the family. They defined a critical time as one of disequilibrium within the family; a time when family needs increase dramatically and when health care professionals are called upon to intervene. These authors also suggest that the initial impact of the child's condition can occur prior to the diagnosis or when the family begins to suspect that something is wrong. These findings support the parents' articulated experience in the current study. Many of these parents described the gradual onset of their child's symptoms followed by the acute and sudden phase of the child's illness. Many recalled the events leading up to the diagnosis as being very frightening, difficult to comprehend and totally devastating. Other parents, whose young children showed few symptoms prior to diagnosis and then quite suddenly became acutely ill, explained feelings of total shock, disbelief and denial associated with the initial impact of the diagnosis. Parents in this study also described themselves as being totally stunned and their lives being turned upside down. These descriptions were congruent with those of Fortier and Wanlass (1984) who reported family anxiety and disorganization, and with Clements and colleagues (1990) who described this as a time of disequilibrium.

Parents in the current study also expressed feelings of denial, anger, sadness and being totally overwhelmed by the situation. Some parents described attempts to block out the experience in order to eliminate some of the initial stress that was almost unbearable. Fortier and Wanlass (1984) described parents as entering a denial stage shortly after a diagnosis had been made of their child's problem. They
described denial behaviour in terms of parents searching for other opinions in the hope that the diagnosis was incorrect, or engaging in wish-fulfilling fantasy. These authors suggest that denial behaviour appears to be a defence mechanism that provides parents with time to face the reality of their situation gradually. In the current study many parents described themselves as "functioning like robots" and being so stunned they were unable to make decisions or be fully responsible for their own actions. Many described feeling out of control or functioning automatically. They denied the complexity of their child’s condition while at the same time describing the experience as hell or a total nightmare. Many did hope the diagnosis was incorrect as manifested in one mother’s description of wanting to believe her own mother who said "it will all go away", rather than believing the doctors who explained that diabetes would be a life-long illness. For some parents in the current study the comparison of their child’s diagnosis of diabetes to other conditions such as leukaemia, meningitis or bleeding problems led parents to initial feelings of relief and beliefs that they could handle the situation because their child was not going to die. Generally, however, parents in the current study described immense feelings of disbelief and the need to block out the experience, which could be equated with Fortier and Wanlass’ (1984) stage of denial.

Fortier and Wanlass’ (1984) also describe a third stage of "grief" that is manifested through feelings of anger, guilt and sadness. They explained that grief may result in blaming others for the child’s diagnosis. Kushion and colleagues (1991) also suggest that guilt feelings are normal in parents when a child is diagnosed with diabetes and should be acknowledged as such by health care professionals. These authors explain that parents may experience high levels of stress and feelings of guilt especially at the time of their child’s diagnosis (p.108). In the current study parents expressed interrelated feeling states of guilt and anger. Guilt often evoked feelings of anger and anger resulted in the parents feeling guilty. In this study parents felt guilty about their child’s diagnosis and also guilty about missing the early symptoms and allowing their child to become so acutely ill. Blaming each other and blaming themselves was an emotional response experienced by parents in the current study. Parents also blamed health care
professionals, particularly lab technicians and doctors who performed painful procedures on their child. They also blamed doctors for delaying the diagnosis in their young child. These responses of blaming are congruent with Fortier and Wanlass’ (1984) findings. However, although no distinct timeframe for resolving these feeling states was provided by Fortier and Wanlass (1984), it is apparent that none of the families in the current study had progressed smoothly through the sequential stages of the model as suggested by these researchers. Instead the parents’ emotions seemed to recur or be sustained, or be experienced in a flood of feelings dependent upon the situation and events occurring in the hospital environment.

The hospital experience

Although I.D.D.M. is one of the more common chronic conditions of childhood (Moyer, 1989) this condition is relatively rare in infants and toddlers (Lipman et al., 1989). Hence, despite the critical nature of the young child’s condition on admission to hospital, no studies have been found by the researcher that describe the stressful events experienced by parents during their infant’s or toddler’s hospitalization. Lipman and colleagues (1989) do describe these young children as being critically ill, often due to the elusive nature of the symptoms and the consequent delay in diagnosis. However, no authors specifically focused on the child’s emergency admission, time spent in intensive care units or the extreme measures required to save the infant’s or toddler’s life and to restore health. Consequently, some of the experiences, reactions and responses described by parents in this study could be used to initiate further research into understanding this aspect of the parents’ experience.

During their child’s initial hospitalization most parents in this study described feelings of utter loneliness, incredible stress, feeling out of control, and helpless and hopeless due to the critical period of their child’s illness. Parents described helplessness when observing their child lying lifeless and comatose, and intense fear that their child would die. Life-saving procedures such as taking blood, intravenous solutions, tubes, monitors, and the constant need for invasive procedures were sources of intense stress.
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The parents' own lack of understanding of their child's condition, lack of privacy, exhaustion and no time to grieve, all exacerbated the parents' level of stress. The alien hospital environment and hospital personnel who performed invasive procedures on the child increased the parents' feelings of loss of control over their situation. On top of this, the magnitude of the task of learning how to care for their child and manage the diabetic regimen left parents in shock and disbelief. All these reactions to the hospital environment and their child's condition appeared to be experienced simultaneously or intermittently. They did not necessarily fit into any clear progression as suggested by researchers who advocate that parents go through distinct emotional stages following a child's diagnosis with a chronic condition (Drotar et al., 1975; Fortier & Wanlass, 1984). However, some researchers have reported that when defects are invisible, such as cardiac defects or diabetes, shock and disbelief may be intensified in parents (Drotar et al., 1975). Diabetes in infants and toddlers is a non-visible condition and because so many parents in the current study expressed feelings of disbelief at the diagnosis and shock over the complexity of the required management regimen for their child, these reports could be justified. However, in this study acceptance of the diagnosis was also influenced by the parents' prior experience with diabetes, and their knowledge of the required management.

Robinson's study (1983) suggests that illness is interpreted differently by each member of the family and will be subjectively interpreted according to past experiences, family beliefs, values and cultural orientation. Other studies confirm that a parent's ability to adapt depends on that individual's past life experiences of coping with chronic illness and ways of feeling about the situation (Anderson et al., 1989; Hayes & Knox, 1984). Findings of this study supported the foregoing researchers' findings. Parents in this study described varying reactions and responses to their child's diabetes. Some were based on no experience with childhood illness at all, some were based on experience with diabetes, and some on experience with other chronic illness. In the current study, past family experiences with diabetes or other long-term health problems significantly affected the parents' feelings about their young child's situation.
Parents who had relatives already experiencing complications from diabetes were devastated by their infant’s or toddler’s diabetes. Conversely, parents who knew family members who were coping effectively with the condition accepted their child’s diagnosis more positively. Parents who had witnessed concerns and panic in relatives with other young children with diabetes felt absolute panic at the time their child was diagnosed. For some parents facing other long-term health problems themselves, diabetes was perceived as a lesser problem. Basing their own perceptions of their young child’s diabetes on past life experiences is a concept well documented in the literature (Anderson et al., 1989; Hayes & Knox, 1984; Vandagriff et al., 1992). For some parents in the current study, responses to their young child’s illness reflected a personal philosophy of life and health while, for others, responses were influenced by culture and heritage. Responses of the extended family also affected the parents’ feelings about the situation.

**Responses to the diagnosis**

Studies show that diagnosis of a chronic long-term illness in a child can have a devastating effect on family lives, and that changes in the health status of a child can alter family interaction patterns, roles, processes and functions (Banion et al., 1983). Freeman (1984) also suggests that, because a family is a system of interdependent parts, a change in any one member creates corresponding changes in all other members. Clubb (1991) also reported that changes in the family’s support structure can occur during a time of hospitalization for a child, or due to a child’s chronic long-term illness. Clements and colleagues (1990) also found that grandparents and extended family members can experience chronic sorrow and mourn the loss of a less-than-perfect grandchild. Clubb (1991) suggests that health care professionals should understand the concepts of changing roles in the family, and that empathy and support should play an important role in nursing interventions (p.464). In the current study most parents described nurses, doctors or other health care professionals as major supports. Some even described the experience of becoming too reliant on health care professionals and experiencing panic at the thought of managing alone at home. Most parents also looked to extended family for support but did not always receive the
anticipated help. Grandparents were reported as being equally stressed and as afraid as parents. They were unable to comprehend the situation or to deal with the complex needs of their diabetic grandchild. Parents were often too busy or too stressed to spend time with extended family during their child's hospitalization. They were also too preoccupied to explain the situation to them. Consequently the extended family became upset and were not very supportive. Although this was not the case with all families in the current study, these findings are congruent with other researchers' findings (Banion et al., 1983; Clements et al., 1990; Clubb, 1991; and Freeman, 1984).

Hayes and Knox (1984) found that participants in their study explained that, in order to be truly supportive, you have to understand the situation and to have been through the experience yourself. Their findings indicated that only parents who had cared for a chronically-ill child themselves truly understood the stresses and anxiety another parent went through. This finding supported parents' accounts in the current study. One family in this study explained that only another mother who had a young infant with diabetes truly understood what she was going through and offered appropriate support. Other families explained they did not want the support of sympathetic grandparents who advised them not to hurt their child, because they knew they had to inflict pain through insulin injections and frequent blood tests in order to keep their child well.

**Buildup of stressors**

As well as coping with the stress of changes in support from extended family members, many parents in the current study indicated stressors they had experienced prior to their child's diagnosis that impacted on their current abilities to adapt. This will be discussed next.

For many parents in the current study the perceptions of their child's diagnosis and hospitalization were described as a culmination or continuation of a multitude of stresses already being experienced in their lives. Researchers McCubbin and Patterson (1982) describe a family "pile-up" of stressors. This occurs when a family is called upon to adapt to another unanticipated and stressful event in an already
stressful situation. These authors suggest that family crisis results from an apparent overload of responsibilities and a pile-up of expected and unexpected life events and hardships. Most of the families in the present study were already coping with the developmental stressor of entering parenthood for the first time, and meeting the challenge of raising their first child (McCubbin & Patterson, 1982). The suddenness of their child’s unanticipated illness also added greater disruptiveness to the parents’ lives. Many of the families in the current study had also experienced other unpredictable stressors such as injury due to an accident in a mother, the loss of a job for a father, and the move from another city creating loss of support systems for another family. McCubbin and Patterson (1982) claim that such a build-up of stressors creates vulnerability in the family and influences the family’s ability to adapt (p.27). Kovacs and colleagues (1991), analyzed self-report symptom inventories and reported that the degree of emotional upheaval experienced by mothers at the time diabetes was diagnosed in their child was a strong predictor of the parents’ later symptomatology (p.276). In the current study parents, who reported extremely stressful experiences in their lives prior to their young child’s diagnosis, also perceived their child’s hospitalization and management regimen as extremely traumatic and difficult to adapt to.

Because the parents’ ability to manage their infant’s or toddler’s diabetic regimen at home depended on what they learned in the hospital setting, this learning experience impacted dramatically on the parents’ total perceptions of caring for a child with diabetes. Consequently, the coping behaviours adopted by parents will be discussed next.

**Coping Strategies Employed by Parents to Manage the Situation**

Coping behaviours identified by parents in the current study were both positive and negative and either contributed to or detracted from the parents’ level of adaptation. Because of the initial acuity of the young child’s condition and the complexity of the management regimen that had to be learnt, parents perceived the hospital experience as being overwhelming and inordinately stressful. Lipman and colleagues
(1989) described the developmental stages of infants and toddlers, and the extra difficulties these stages superimposed on the parents as they mastered the everyday tasks of managing the diabetic regiment. These authors described how much more difficult it was to acquire competence in giving insulin injections, monitoring blood sugar levels and modifying the diet for infants and toddlers. They described the infants’ developmental stage as "trust versus mistrust" (Erikson, 1964) and suggested that, for the infant who is just learning to trust those who provide comfort, diabetes poses a major stumbling block. Suddenly, the most trusted person in the infant’s environment, his mother, must inflict pain on him repeatedly. The mother, who is also used to seeing herself as the infant’s source of comfort, feels extreme anxiety at the thought of causing her own baby pain. These authors also suggest that the daily task of repeated blood glucose testing on the tiny fingertips is a major source of stress for both the infant and parents. Any child who is hospitalized during this crucial development stage needs the parents with him/her constantly, and parents require constant support and reassurance that what they are doing is absolutely necessary (Lipman et al., 1989). Lipman and colleagues (1989) also discussed the developmental stage of toddlers as "autonomy versus shame and doubt" (Erikson, 1964). They explained that, for the toddler, diabetes gets in the way of the need to explore and experience their world. Toddlers are also extremely frightened of painful procedures and totally overwhelmed by insulin injections and blood testing. Parents are required to restrain and inject a struggling, protesting child and the event is extremely stressful for both toddler and parent. Toddlers also tend to mimic parents. Therefore, if the parent approaches a procedure with trepidation or fear, the child senses this immediately and becomes more terrified. The support of nurses who teach these procedures is crucial and the methods used in the teaching/learning situation can influence the adaptation of both the parent and the child. Like most studies, Lipman and colleagues discuss only the mother as the primary caregiver, yet the current study indicates how crucial the father’s role is in sharing responsibility for the day-to-day management of the young diabetic child.
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In a qualitative research study of parents' hospital related stress, Hayes and Knox (1984) sought stress-related information concerning description (pathophysiology), cause (etiology), symptoms, degree of concern, and management, as well as information pertaining to how parents manage stress when their chronically-ill child is hospitalized. These researchers also examined the parents' perceptions of health care professionals' roles in stress management. Hayes and Knox (1984) used Kleinman's (1978) framework to guide their study. They also collected data through tape recorded interviews in a similar design to this current study. Hayes and Knox (1984) interviewed 40 parents of children hospitalized with cancer and other long-term illnesses. These children were all beyond their initial diagnostic and induction periods and were not necessarily infants and toddlers. However, the study findings were relevant to this current study. Parents participating in the Hayes and Knox (1984) interviews discussed their stress and anxiety associated with painful, invasive procedures for their child in the hospital environment. They also discussed how much they were affected by their child's moods and feelings. One mother in this study described the pain she felt each time her child was poked. Others explained how much the hospitalization affected the parents as well as the child. These finding are congruent with the current study data, in which parents expressed fears of giving injections, horror at poking infants' already bruised and bleeding fingertips, and pain when they attempted these procedures on themselves. In the current study all but one father attended the teaching sessions with the mother, and was encouraged to participate equally in the child's care. In striking contrast, the mother was perceived as the primary caregiver in the Hayes and Knox (1984) study.

Parents in the Hayes and Knox (1984) study were found to be concerned about the quality of information they received. They also explained the need for information that was detailed, presented clearly and concisely, repeated often, stated in easy to understand terms and offered at times when the parents were able to listen and to absorb the information (p.337). Most parents in the current study reiterated these needs. However, in contrast to the findings in the Hayes and Knox (1984) study, some parents in the current study explained that the technical approach to teaching and the specific and precise
instructions offered by health care professionals filled them with panic. These parents expressed their own feelings of incompetence. They felt resentment towards health care professionals because they were not always treated as responsible parents who were able to rationalize and make decisions. Because the parents in the current study were experiencing their young child's initial hospitalization, and were required to master the tasks of managing the complex diabetic management regimen, their experience was quite different from that of parents in the Hayes and Knox (1984) study. However, conclusions reached in both studies were similar. In both situations it appeared that parts of the parents' difficulty and stress was related to delineating their parental role in the hospital setting (Hayes and Knox, 1984, p.336). Establishing the parent role or adapting to parenting in the hospital environment was perceived as a major source of stress by participants in both studies. In both situations the parents' perceptions of the manner in which they received information differed from the perceptions of health care professionals providing the information. In both studies the parents portrayed their fears about their children's management and their lack of control over the situation. Also, participants in both studies articulated that the health care professionals' conception of the parents' role in hospital care of their child was not always congruent with the parents' model. This in itself was a source of stress. However, in the current study all the infants and toddlers but one were the first child in the family, and parents all described how inexperienced they were at being a parent, let alone the parent of a child with such special needs. Nonetheless these parents perceived the need to be assertive and to advocate for their child in certain stressful situations that became unbearable to them. Likewise the parents in the Hayes and Knox (1984) study also perceived themselves as mediators and interpreters for their hospitalized child. However, in contrast, the parents in the Hayes and Knox (1984) study considered themselves experts in evaluating their child's needs, whereas parents in the current study considered themselves complete novices. Another significant difference in the findings of these two studies is that parents responding to the Hayes and Knox (1984) study viewed physicians as the primary source of information, whereas parents in the current study viewed nurses as their primary
source of support and information. This could be a reflection of the major role nurses play in the multidisciplinary diabetic management team, and their mandate to provide support and education for the families of children with diabetes.

Kushion and colleagues (1991) suggest that, when possible, the initial hospitalization is an excellent time to educate alternate caregivers along with the rest of the family, and that specialized education for ancillary caregivers should also be offered in an outpatient setting. They recommend that basic survival skills such as injection techniques, blood sugar testing and treatment of hypoglycemia should be offered by health care professionals and not left to the parents to teach these concepts. When identifying their needs, parents in the current study reinforced the advantages of such services, and explained how supportive and reassuring this would be for them. Explaining and describing their child’s condition and needs to others was a difficult task for parents in this study. Most felt they were so inexperienced and confused themselves that it was impossible to explain things to others. Parents described feelings of utter frustration, inadequacy, incompetence and not even knowing how they felt or what they needed themselves let alone trying to explain to others. One father in this current study spent immense amounts of energy trying to understand and explain his young son’s condition.

Understanding and describing the child’s condition

Canam (1987; 1992) explained that coping with a child’s chronic illness presents many challenges for parents. To cope effectively there are a number of adaptive tasks that parents should complete. One of the most important of these tasks is being able to communicate with others in the family about the child’s illness and to explain the situation to them. However, Canam (1987) reports that little research has been done in this area. Canam’s framework which includes the eight parental adaptive tasks of accepting the child’s condition; managing the child’s condition; meeting the child’s normal development needs; meeting the developmental needs of other family members; coping with ongoing stress and periodic crisis; assisting family members to manage feelings; educating others about their child’s condition; and
establishing a support system, will be referred to as it pertains to the parents’ perceived experience during the rest of this discussion on the study findings. Canam’s (1992) framework was developed for utilization by health care professionals working with parents of chronically-ill children. Accomplishing the first task of "accepting the child’s condition" was described as being dependent upon the presence or absence of explanations which helped the family make sense of the child’s diagnosis. Also, participants revealed that comparing their situation with that of other parents who have a chronically-ill child can positively change a parents’ perception of their own situation. This coping behaviour of comparing their child’s condition with alternatives was displayed by parents in the current study. Most parents compared their infant’s or toddler’s diabetes favourably against other chronic illnesses in children. Defining their child’s situation within a previously existing philosophy was also a coping strategy used by some parents. However, total acceptance of their child’s condition was not accomplished by all parents within this phase of their experience. Many maintained an almost false optimism of an early cure which they explained as a motivating factor to help them cope with the immensity of their task and to carry on. Some had difficulty accepting the diagnosis and falsely believed it would "all go away". Due to extreme anxiety, feelings of inadequacy and loss of control or ability to make decisions, parents learned only basic survival tactics at this time. Stress also interfered with parents’ ability to comprehend all the information provided. Canam (1992) suggests that the nurse clinician is one of the most important sources of information for the day-to-day management of the child’s condition, and should be cognizant of the barriers affecting the parents’ ability to learn. This researcher also suggests that educating others about the child’s condition, and assisting family members to manage feelings is an important facet of clinical nursing practice. As previously described, parents in this current study were unable to identify their own needs or feelings, let alone attempt to deal with extended family members during their child’s hospitalization. Canam (1992) explained that families in crisis need to be helped and supported through the crisis situation before any adaptive tasks can be accomplished. The stress described by the parents in the current study, and the crisis
intervention required by parents during their child’s hospitalization, confirmed Canam’s explanation that the timing of information given to parents must be matched to the parents’ emotional readiness to understand its relevance (1992, p.11). However, in order to take their child home, parents in the current study had to grasp the basic meaning of their child’s required management.

**Feeling trapped**

Because of the magnitude of the task of caring for an infant or toddler with diabetes, many parents in the current study attempted to deny or avoid their responsibilities until they realized there was no viable alternative.

Parents who initially resisted acceptance of the required treatment regimen for their child, later realized they had no choice in the matter and that there was no way out. Despite this realization, parents were left feeling vulnerable and trapped. Robinson (1983) found that families generally coped very well with the demands of a long-term illness in a child which seemed to be a reflection of their attitude that coping is not a choice-making issue. However, the enormity of the demands of the diabetic regimen for an infant or toddler has not been previously researched.

Looking for a cause was another coping behaviour adopted by parents in this study. For many parents, this strategy was used as a means to resolve guilt and blaming, and to reduce stress. However, because of the complex etiology of diabetes, few parents gained satisfaction from this pursuit. Instead, meeting the demands of the complex regimen, and understanding the need for such procedures once they took their child home, became the all consuming task for parents in this study.

Findings of this study revealed that parents experience multiple and coexisting stressors at the time their infant or toddler is diagnosed with diabetes and admitted to hospital. The acuity of the child’s condition at diagnosis, the alien hospital environment, the constant need for invasive procedures, and the magnitude of the task of learning how to manage their child’s condition exacerbated the parents’ stress and dramatically shaped their early experience. Literature reviewed on the topic described the diagnosis
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of a chronic long-term illness in a child as being a critical time of extreme anxiety, disequilibrium and disorganization within families. Other authors also described the stress and anxiety related to painful intrusive procedures for the hospitalized child. However, no studies have been found that relate specifically to the experiences, reactions, responses and coping strategies described by the parents in this study. Consequently, findings of this study could be used to initiate further research into understanding this phase of the parents’ experience.

Phase Two: Caring for the Young Child at Home

During this phase of their experience parents in the current study assumed full responsibility for the day-to-day care of their young diabetic child at home. The widespread implications and pervasive influence of diabetes on the entire family system became apparent to parents at this time.

For the purpose of the following discussion, findings related to the parents’ perceived stressors and resultant struggles will be presented together with the parents’ emotional responses and reactions to their situation. The coping behaviours employed by parents to manage their child’s condition will then be related to pertinent findings in the literature.

Perceived Stressors and Parents’ Responses to the Situation

Many of the stressors identified by parents during this phase of their experience related to events and situations over which they perceived they had little control. Taking the child home, making necessary changes in lifestyle, perceived losses, the uncertainty of their child’s hyperglycemia and hypoglycemia, giving injections, doing blood tests and worrying about developmental issues for their child were all stressors impinging upon these parents. Emotional responses to their situation and reactions to changing roles and relationships resulted in friction and conflict. Parents were left feeling emotionally and physically exhausted, and they described this period of their lives as being one of simply surviving and not really
The following comparison of findings with those in the literature will begin with the implications of taking the child home and accepting the required changes in lifestyle.

**Taking the infant or toddler home**

Parents in the current study described taking the child home as a frightening experience. Although the acute phase of the child’s illness was over, the magnitude of the task of caring for their child without the support of hospital staff was overwhelming. Most parents were exhausted due to the stress and demands of the hospital stay, and the fear of hypoglycemia for their young child was already perceived as a major stressor. Parents were unable to relax. They fretted over their child’s blood sugar levels and perceived themselves as riveted to the inflexible and all consuming management regimen.

Parents in this study explained that having an infant or toddler with diabetes changes their whole life and that they would never experience life again as it was before their child’s diagnosis. Ironically, parents in the Hayes and Knox (1984) study used virtually the same words to describe their situation. These researchers quoted parents as stating "having a chronically-ill child changed our whole life and we will never return to life as it was before our child was diagnosed" (p.335). Clements and colleagues (1990) suggested that the disruption caused by the initial impact of the child’s diagnosis and hospitalization may continue for months post diagnosis. These researchers also reported that families who had experienced extreme stress in the hospital situation were more likely to experience prolonged stress and disruption at home. This finding was supported in the current study when parents, who had reported a build-up of stressors prior to their child’s diagnosis, also described their child’s hospitalization as a devastating experience, and further described their early months of coping at home as totally overwhelming and a nightmare experience. Conversely, parents who had viewed their infant’s or toddler’s diagnosis philosophically, and had managed the child’s hospitalization with relative calm, described the homecoming experience as slightly less stressful. However, without exception, all parents in the current study were
implicitly tied to their child’s imposed schedule in the belief that to deviate would cause irretrievable harm to their child.

Freeman (1984) reported that when illness occurs in a child, the child often becomes the principal directing force and, as such, causes major responses in each of the other family members. Findings in the current study confirm that the infant or toddler with diabetes becomes the directing force in the family, and that the parents’ lives revolved around the child’s needs and the demands of the required management regimen.

Several theorists report that the majority of difficulties experienced by parents centre on extensive treatment regimens, and that these regimens are so demanding that they pose a greater problem for the family than do the symptoms of the child’s long-term illness (Bouma & Schweitze, 1990; Chan & Leff, 1982; McCollum, 1981). Other researchers have specifically cited diabetes as a chronic life-long illness that affects not only the life of the child but the life of the entire family because of the daily demands of the complicated management (Betschart, 1988; Brink, 1987; Hatton, 1988; Hunt & Alajado, 1989; Krall & Beaser, 1989; and Tze, 1989). In this current study the parents reported significant lifestyle changes that occurred immediately following the infant’s or toddler’s diagnosis. For example some parents’ work schedules had to be changed to accommodate the giving of insulin which required that two parents be present; one to inject and one to restrain the struggling child. Fathers were required to give up social pursuits in order to be home to handle certain aspects of their child’s care. The imposed rigid regimen led parents to exhaustion and frustration and fears that they would never handle the situation. Because of the very specific instructions provided by educators in the hospital the parents perceived no room for flexibility. Although parents in the study each perceived their situation in a unique way, the outcome for all was constant. A change in lifestyle was required. Parents described the diabetic regimen and its restrictions as taking the fun out of life. Food restrictions curtailed the preparation of favourite meals and the pleasure of going out to eat. Fear of hypoglycemia made eating for the child a necessity not a pleasure.
During confrontations over food with their infants or toddlers, parents described the experience of feeding "that monster called insulin and not the child", or "managing and taking care of the diabetes and not the child". For most parents the pleasure of bringing up their first child was exchanged for a routine of blood tests, insulin injections and worries about blood sugar levels. In Betschart's (1988) study, results indicated that parents and children with diabetes face numerous difficult tasks every day, and that the process of accepting the diagnosis of diabetes is similar to that of mourning (p.400).

One of the common adaptive tasks outlined in Canams' (1992) framework is that of accepting the diagnosis. Many parents in the current study described an ongoing mourning process that was sustained by the constant reminder of their child's condition due to the management regimen. This process of mourning could be related to the chronic sorrow concept introduced by Clubb (1991). In her study, Clubb (1991) cited several other studies that had examined the adjustment patterns of both mothers and fathers. Most found that fathers reported their adjustment as time-bound, whereas mothers described a chronic sorrow pattern. However, most of these studies were conducted on physically or cognitively impaired children's parents. Clubb (1991) suggested that qualitative research into the adjustment patterns of parents of chronically-ill children is clearly needed. Most parents in the current study appeared to adjust in a similar way and to follow the three distinct phases of the experiences constructed from the parents' accounts. Also, from the current data, no clear delineation between the mothers' and fathers' adjustment patterns could be made. However, many variables such as the age of the child at diagnosis, the length of time since diagnosis, the parents' past experience with diabetes or the number of support systems available, all impacted on the parents' perceptions of their experience and their ability to adjust.

Banion and colleagues (1983) reiterated that the younger the child at diagnosis and the shorter the duration of the illness, the greater the parents' concern about the child's diabetic management, and the more difficulties experienced by parents in their attempts to adjust.
Perceived losses

In describing their many lifestyle changes, parents in the current study described these changes in terms of losses.

All parents in the current study described losses in their lives due to the many changes imposed by the child's daily management regimen. These losses were perceived as extremely stressful and disruptive, and induced periods of mourning. Parents described loss of flexibility, spontaneity, freedom, support systems, and intangible losses which were difficult to explain. Loss of flexibility, spontaneity and freedom were all attributed to the demands of their child's diabetic regimen. Feelings of being trapped, or being a prisoner tied to their child's diabetes were described by parents, and the loss of support systems was perceived as a major source of stress. Because they were so tied to their child's routine, parents were unable to get out, to visit friends or to socialize. As a consequence, loneliness and social isolation was experienced. From the parents' accounts, the younger the diabetic child, the greater the loneliness experienced.

Although loss of support and consequent social isolation for the chronically-ill person has been discussed frequently in the literature, no studies were found by this researcher that focused on loss of flexibility, loss of spontaneity or loss of freedom for the parents of young chronically-ill children. Most studies on diabetes focused on issues pertaining to older children, such as interactions with peers or socialization at school. It has been acknowledged (Betschart, 1988; Anderson et al, 1991) that all diabetic children and their families are bound by the rigidity of the management regimen. However, the extent to which the parents of infants and toddler with diabetes are affected by this problem has not been fully examined. Further study of this unique population is indicated.

In this current study, the parents' feeling of total responsibility for their young child's life and very survival was paramount. They described being constantly vigilant in thinking, feeling and anticipating for their child who was too young to understand or communicate his or her own needs, or take any
responsibility for his or her own care. Parents mourned their own losses, but also mourned the loss of freedom for their child. The burden of responsibility for their child led parents to a fear of leaving their child with others. A subsequent reluctance on the part of relatives and friends to become involved and take over some responsibility for the child contributed to the parents’ feelings of loneliness, abandonment and social isolation.

In the current study parents admitted to being reluctant to trust others with their child. They described feeling inadequate and fearful themselves. Consequently, they understood why others had difficulty accepting the responsibility. Nonetheless, they felt depressed. Kushion and colleagues (1991) suggested that social isolation and resulting depression is accentuated in the parents of infants and toddlers with diabetes. They recommended that health care professionals should acknowledge the problem, and intervene by providing support and education for grandparents, babysitters and other possible support systems such as daycare workers. It was clear from the parents’ accounts in the current study that a lack of understanding existed as to the issues families of such young children with diabetes encounter. Some mothers explained their desire or need to return to work if only on a part-time basis. However, finding care for their child was difficult. Consequently, the parents’ life as well as the financial status of the family was affected. Kushion and colleagues (1991) identified similar issues, and recommended that more studies which could provide a greater understanding of these young families’ needs should be conducted. Parents in the current study also described the loss experienced by grandparents due to their inability to handle the young child’s needs and the resulting alienation from their grandchild. Few studies were found by this researcher that address the special needs of grandparents.

Intangible losses described by parents included loss of happiness, loss of a normal child, loss of opportunities for themselves and for their child, and loss of the pleasure of knowing how their infant or toddler might have been without diabetes. The stress of the management regimen was seen as changing parent/child interactions, leading to a loss of closeness that would never be recovered.
Contemplating these losses led many parents to severe depression, and some even contemplated suicide which was extremely frightening. These parents did seek professional counselling. Although studies such as Kovacs’ and colleagues (1991) reported on maternal depression and psychological distress resulting in neurotic behaviour for parents of children with diabetes, no studies are available that address the severity of the depression experienced by the parents of infants and toddlers.

Although much of the parents’ distress and depression was related to perceived losses, the unpredictability of their child’s blood sugar levels and fear of hyperglycemia and hypoglycemia also contributed to their emotional turmoil.

*Unpredictable blood sugar levels in a young child*

The unpredictable nature of diabetes in infants and toddlers was a major factor contributing to the stress experienced by parents in the current study. Parents described the pervading and overriding stress of unpredictable blood sugar levels and their inability to control them. Fear of hypoglycemia and hyperglycemia led to changes in attitudes, and the parents’ fear to leave their child or to trust others. The dichotomy between the fear of long-term complications due to hyperglycemia and the fear of seizures due to hypoglycemia resulted in sustained ambivalence and confusion for parents. This emotional ambivalence was experienced on a continuum into Phase Three of the parents’ experience. Dealing with infant’s and toddler’s mood swings, and attempting to differentiate normal toddler behaviour from blood sugar level induced behaviour, was a constant struggle fraught with frustration, anger and psychosomatic reactions in some parents. In this current study, parents described a roller coaster of emotions corresponding to their young child’s rapidly fluctuating blood sugar levels. They asked “what have I done wrong?” or “why can’t I control this?” Because of a fear of long-term complications parents described “feeling sick” or having a “knot in their stomach” when they saw high blood sugar readings. Similar feelings, plus absolute panic was experienced if low blood sugar levels were detected. Because of the lability of their young child’s
condition, the early months following the diagnosis of diabetes were described as unbelievably stressful by these parents.

No previous studies were found that specifically focus on the parents' responses to the unpredictable nature of an infant's or toddler's diabetes. However, experiential articles which focus on issues related to care of diabetic infants or toddlers attest to the incredible stress of the parents of these young children, in particular with regard to hypoglycemia (Lipman et al., 1989; Kushion, et al., 1991). Although parents in the current study were concerned about hyperglycemia, this worry was limited. Most parents still maintained a hope for a cure for diabetes before their child reached adulthood. Consequently, their focus was on the immediate threat of hypoglycemic episodes and not on long-term complications. Marteau and colleagues (1987) emphasized that parents of children with diabetes are generally more concerned about the immediate threat of hypoglycemia. Because diabetes is a hidden problem, Marteau and colleagues (1987) suggested that parents lacked understanding of the long-term implications of hyperglycemia. Consequently, the goals of parents and the goals of health care professionals was one of maintaining tight diabetic control for children and preventing long-term problems; the goal of parents was to prevent the immediate threat of hypoglycemic seizures.

Recently, new research studies have presented findings that lend credence to the parents' concerns about hypoglycemia, particularly in the very young child. These studies provide information that suggests frequent and unrecognized hypoglycemia in an infant or toddler can result in central nervous system damage for the child and that, probably because the brain is still undergoing development in such young children, hypoglycemia can go unrecognized (Kushion et al., 1991; Puczynski et al., 1992; Rovet, Ehrlich & Hoppe, 1988; and Ryan, Vega & Drash, 1985). These findings suggest that even health care researchers have conflicting views on the seriousness of hyperglycemia versus hypoglycemia in a child with diabetes which can be an additional source of stress for parents.
Fear of hypoglycemia

Because infants and toddlers cannot tell their parents when they are experiencing symptoms of hypoglycemia, parents often live in fear of this occurring without their knowledge (Clubb, 1991). Banion and colleagues (1983) also found that the younger the child the greater was the maternal concern about hypoglycemia. Results of the current study confirmed that parents of infants and toddlers with diabetes experience inordinate amounts of fear concerning the possibility of hypoglycemic episodes for their child.

Kushion and colleagues (1991) reported that hypoglycemic seizures are a major problem for families with an infant or toddler with diabetes. Factors contributing to the frequency of profound hypoglycemia in this age group include the inability to force-feed the child, erratic activity patterns, the need to frequently change insulin doses, and episodes of diarrhoea and vomiting. These authors suggested that parents often go to extreme measures to prevent hypoglycemia in their child. Marteau and colleagues (1987) also reported that hypoglycemia is frightening for parents. The fear that their child might die led parents to the belief that a higher glycemic level was preferable and that hypoglycemia should be avoided at all costs (p.29).

Findings of the current study confirmed all the foregoing researchers’ results. Parents in this study adopted extreme measures to prevent or treat hypoglycemia. They purposefully kept their infant’s or toddler’s blood sugar level elevated, they installed intercom systems into their child’s bedroom or, alternatively, moved the child into their own bedroom or into their own bed at night time. They experienced utter panic if their child wouldn’t eat, and strapped the child into a high chair and force-fed continually. One young mother described feeding her six-week-old infant chocolate chips and honey when she discovered a low blood sugar, even though the infant showed no signs of hypoglycemia. Lipman and colleagues (1989) explained that infants cannot express feelings of symptoms of hypoglycemia. Nor are these young children likely to demonstrate the epinephrine-induced symptoms of classic hypoglycemia. Consequently, an infant can become unconscious or seizure without much warning (p.256). Parents must
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monitor blood sugars frequently to understand peak times of insulin action, and to detect falls in blood sugar levels which can be quite dramatic (Kushion et al., 1991). The necessity to feed the child in order to prevent hypoglycemia is a major source of stress for parents.

**Confrontations over food**

Parents in the current study described the experience of getting the child to eat as a major source of stress. The need to prevent hypoglycemia through feeding the child led to confrontations, and many parents described force-feeding their child. Parents in this study perceived insulin as a powerful substance that could be extremely dangerous if the child wouldn’t eat. Consequently, they became fanatical about providing meals and snacks on time, and totally vigilant and inflexible about testing blood sugar levels before meals and giving insulin injections on time. They were horrified of deviating from the prescribed regimen. As a consequence, parents often adopted inappropriate behaviours such as strapping the child into a high chair and feeding him/her continually. In response, the young child developed behaviour problems such as temper tantrums or vomiting. Parents described "food as ruling their lives", and the constant focus on food was a major concern to parents.

Kushion and colleagues (1991) described "finicky" eating patterns as an extremely disruptive factor in the parents’ attempt to maintain an adequate nutritional balance for the young child with diabetes. They saw eating habits as being especially challenging in the battle to maintain good glycemic control for the child. They recommended that imagination and patience were vital and that parents required support and constant insulin changes for their child in order to prevent food intake from becoming a battleground. In older toddlers, hunger and temper tantrums over lack of food led to children stealing food or stuffing food into their mouths and not swallowing. These behaviours frustrated and saddened parents. Parents described feeling mean and sad when they had to refuse their hungry toddler food. Vandagriff and colleagues (1992) concluded that parents of younger children with I.D.D.M. reported more worry overall that did parents
of older children with diabetes (p. 301), and that these parents should be targeted for interventions to assist them in finding ways to handle their young child’s behaviour.

**Giving injections**

Another source of stress, and one that requires constant nursing support, intervention, innovation and suggestions to ease the parents’ struggle, is the giving of insulin. Because of a paranoia or often intense fear of needles, the giving of insulin injections constituted an ongoing stress for parents that should not be underestimated. The fear, the guilt and the sadness evoked in parents each time they restrained and injected a struggling, protesting infant or toddler was experienced on a continuum from the first phase of the hospital experience and often continued into Phase Three for the parents in the current study. Lipman and colleagues explained that because of the young child’s developmental stage and inability to understand, the fear and dislike of being restrained is almost as psychologically stressing for the child as the injection itself. Giving a toddler a choice, even of the injection site, can overwhelm him/her because making a choice is almost beyond the young child’s control or ability (1989, p. 256). Toddlers are also very strong and extremely difficult for one parent to handle at injection time. Betschart (1988) reports that inflicting pain and suffering on their very young child can contribute to both physical and psychological stress in parents. In the current study, the parents’ reactions to the invasive procedure of insulin injections were congruent with the findings in other studies. However, reactions to the procedure of doing blood tests were strikingly different.

**Blood sugar testing**

MacMillan and colleagues (1988) conducted a study to evaluate a program implemented to teach nurses the techniques of successful blood glucose monitoring. They concluded that not only did this added component to an already complex and demanding diabetic regimen stretch the resources of nurses, but that it would require inner strength and resourcefulness on the part of parents to perform this task on a daily basis at home. However, a study conducted by Templeton and colleagues (1988) concluded that the
invasive procedure of blood glucose monitoring provided parents with feelings of control, indications of
good and bad diabetic control, helped to confirm hypoglycemia and hyperglycemia, and allowed more
flexibility in the dietary regimen and insulin administration. Findings in the current study supported both
these studies but supported the MacMillan and colleagues' (1988) findings to a lesser degree. Surprisingly,
despite the intense stress and anxiety experienced by parents due to blood sugar monitoring for their child
in hospital, most parents in this study described blood testing as being less stressful once the child was
home. Parents described their absolute vigilance with methodical and frequent blood testing as being an
essential element of the management regimen. However, they also described the actual process of
obtaining the blood sample as acceptable to most toddlers who often participated in the procedure. All
families in the study tested their infant’s or toddler’s blood at least four times daily and some even more
frequently. For most parents, the most stressful part of this procedure was obtaining the results. Most
parents described a dread of seeing exceptionally high or low readings. However, most acknowledged that
these results were imperative to their peace of mind, and their lifeline to interpreting their young child’s
moods and behaviours. Although parents did not learn how to use the results for manipulating insulin or
diet until Phase Three of their experience, each parent did acknowledge that they used their child’s blood
sugar results as a guideline for differentiating diabetes related behaviour from normal toddler behaviour
even during the early months of their managing their child’s condition. These findings in the current study
were contrary to those of Lipman and colleagues (1989) who reported the extreme anxiety experienced
by parents when pricking an infant’s or toddler’s tiny fingertips and inflicting so much pain. In this current
study, parents reported an ability to prick an infant’s or toddler’s finger to obtain a blood sample even as
the child slept. The procedure did not even waken the child, which was a constant source of amazement
to parents.
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Because of the young age of the child at diagnosis, the task of differentiating normal toddler behaviour from diabetes-related behaviour was difficult. Consequently, the blood tests were perceived by parents as "the only way of seeing what was going on inside the child, and how the insulin was working".

**Child’s development**

All parents in the current study described some knowledge deficit with regard to parenting skills and understanding the normal growth and development of their child. Because all but one of the children in the study were the first child in the family, the child’s development was identified as a major concern to all parents. Some parents in this study saw their toddlers as being less coordinated, lagging in motor development and more timid since their diagnosis with diabetes. Some parents rationalized that this developmental delay could be related to the pre-diagnosis months of lethargy, poor appetite and polyuria. Others felt they overprotected their child because of the diabetes and that this overprotection caused a lack of confidence and ability in the child. Kushion and colleagues (1991) suggested that infants and toddlers might sense their parents’ concern, and respond with behaviours of regression and developmental delay. Lipman and colleagues (1989) reported that young children may have a setback in self-esteem and be fearful to explore their world.

A surprising contrast observed in this current study was reported by parents of infants who had been diagnosed at only a few weeks or months of age. It appeared to parents that these infants matured more rapidly than their peers, were well ahead in developmental milestones both cognitively and physically, and were often aggressive, assertive toddlers. Parents attributed this to the amount of attention and parental time these toddlers had received, and the need for the infant to cope with the rigors of the daily regimen. No documented evidence in other studies was found to substantiate these findings.

Generally in the current study, parents were extremely concerned about their young child’s cognitive and physical development and felt disadvantaged by their lack of knowledge of normal milestones with which to compare their child’s progress. Parents definitely compared their young child
with peers and, because the insulin deficiency was a hidden defect, wanted their child to maintain normal
developmental milestones. Clubb (1991) reported how important it was for parents of chronically-disabled
children to compare their child’s development in relation to normal children. This researcher suggested
that guilt and grieving resurfaced if the child did not develop normally and that peaks of chronic sorrow
could be experienced if the child was not perceived as normal. Although diabetes does not cause outward
signs of disability, parents did describe grieving when babysitters or others referred to their infant or
toddler as "not normal". Some parents did consider their young child as abnormal. During this phase of
their experience, and the inflexible regimen was a constant reminder to the parents of their child’s
abnormality (Moyer, 1989).

Parents in this study described an ongoing grieving process and sustained feelings of "why me",
"why our child" or "why us". They also described the experience of "crying inside", "cringing", feeling
"physical pain" and "sadness" when their young child protested. However, they had to proceed with certain
aspects of the management against the child’s will. This led to changes in roles and relationships and often
resulted in conflicts and friction.

Roles, relationships, conflicts and friction

Kushion and colleagues (1991) report that parents of infants and toddlers with diabetes may
experience increased conflict in their own relationship. Wysocki and colleagues (1989) also reported that
mothers of pre school-aged children with I.D.D.M. experience more stress in the family which they
attribute to the diabetic child. Some authors suggested that conflict often arises over responsibility for
giving injections or testing blood sugar levels. Parents may take less time for themselves as a couple
because they feel guilty about time spent apart from their child. The impact of conflict and stress on the
family’s ability to cope and manage I.D.D.M., as well as the child’s physical and emotional well being,
should be constantly monitored by health care professionals (Kushion et al., 1991, p.109). In the current
study, parents reported major changes in roles and relationships. Fathers’ socialization habits were
changed due to the necessity for them to participate in their child’s management. Mothers delayed returning to work, or else were forced by circumstance to stay home with their diabetic youngster. The demands of the regimen led to tension between parents, and the roles of previously supportive grandparents changed. This led to changed interaction patterns between child and grandparent. Some parents discussed changes in relationships between mother and child due to the parents’ need to inflict painful procedures or to force-feed the child if necessary. These findings were supported in a study by Betschart (1988), who suggested that parents’ feelings of guilt and frustration over the need to inflict pain and suffering on their child continually might contribute to parental behaviours of child abuse, psychological neglect and inability to provide love and security for the child. Betschart (1988) also found that parents’ understanding of, and guilt over their child’s diabetic control frequently led to stress and conflict not currently being addressed by health care professionals. Betschart’s findings were supported in the current study. Some fathers in this study reported a preference for keeping their infant’s or toddler’s blood sugar levels low in order to prevent the possibility of long-term complications for the child. By contrast, in the same families, the mother preferred to keep the young child’s blood sugars higher due to their intense fear of hypoglycemia. In each case the utter frustration of being unable to control the rapidly fluctuating blood sugars in the child led to increased friction and blaming.

One of the unusual findings of the current study compared with all other studies reviewed by this researcher was the amount of interest and involvement in their young child’s welfare displayed by fathers. Several parents also reported that the child’s diabetes had created a special closeness and bonding between the father and the child. Many fathers in this study assumed a major role in giving insulin injections and performing blood tests for their child. These fathers were reported to handle these invasive procedures more competently than the mother, and to approach the procedures with games or unique methods that made them more acceptable to the child. Fathers also became much more involved in their child’s social life and general care and formed a stronger bond with their young child than they had before the diagnosis
of diabetes. This finding was contrary to that of Clubb (1991) who reported that, in general, the father of a chronically-ill child assumes primarily an instrumental role, whereas the majority of the caretaking role is assumed by the mother. Clubb (1991) suggested that this delineation of roles is characteristic of normal families, but is even more pronounced in families with children with disabilities (p.464). Despite the acknowledgement of the fathers’ need and desire to be involved in their infant’s or toddler’s care, some mothers did report an overwhelming feeling of guilt that they had in some way contributed to their child’s diabetes and, consequently, should be totally responsible for the child’s care. These mothers did temporarily shut fathers out, and their description of the stress and depression experienced by both parents during these periods of misunderstanding and conflict only accentuated the need for health care professionals to better understand the parents’ stress and to intervene by providing support and a forum for parents to articulate their concerns.

Conflicts and frictions reported by the parents in the current study were also related to exhaustion, frustration and inability to communicate with each other. Parents often felt lonely and isolated due to the changing relationships with extended family and friends. The need to be completely absorbed in their young child’s care often alienated parents from others and resulted in arguments between the parents. However, parents recognized their child’s need for both of them, and their need to support each other. Clubb (1991) reported that marriages appeared to remain stable regardless of the child’s disability. McCollum (1981) reported similar findings in families who have chronically-ill children. This author suggested that, although the child’s illness calls for a period of adjustment in parents, marriage breakdown is rare. In the current study, one family who had been experiencing marital stress prior to their young child’s diagnosis saw the diabetes as a catalyst for bringing the family back together again. However, in most instances, parents’ perceived their child’s diabetes as a monster that continually threatened their ability to cope. The coping behaviours adopted by parents will be presented next.
Coping Strategies Employed by Parents to Manage the Situation

Implicit in the parents’ accounts of this current study were a set of goals related to ensuring that the infant or toddler was adequately cared for. These goals were related to the parents’ perceived commitment to manage the regimen, make good decisions, share responsibility, interact with health care professionals, trust others, identify their own needs, and maintain hope. Many of these adaptive tasks can be equated with Canam’s (1992) parent adaptive task framework. The tasks of accepting the child’s condition and managing the condition on a day-to-day basis were attempted by parents during this phase of their experience.

Managing the daily regimen

Ensuring the future well-being and health of their child was a foremost goal for all parents in the current study. They considered being methodical and being vigilant as essential elements of the management regimen. These coping strategies were applied to tasks such as preparing food, getting the child to eat, managing hypoglycemia, dealing with unpredictable blood glucose readings, monitoring blood sugar levels and giving insulin injections. Parents perceived no flexibility in the management process and, consequently, tended to mould their lives around the young diabetic child’s needs. Even when a little flexibility was called for, parents initially had difficulty with this concept. Instead they stayed riveted to what they had been taught in the hospital. Moyer (1989) suggested that, in the early years, the burden of the relatively inflexible dietary and insulin regimen, and constant surveillance of blood glucose levels, falls squarely on the parents. Her study indicated that a systematic assessment of parent coping is necessary if specialist nurses are to help parents in their role as primary health carers (p.536).

Canam (1992) suggested that families of chronically-ill children who functioned poorly are seen as those in which the parents believed they had an impossible assignment. Parents in the current study initially had definite feelings of being unable to cope. However, by receiving constant information through telephone contact with health care professionals who could offer advice, each family did cope adequately.
Canam (1992) suggested that receiving adequate and complete information about their child’s disease and its treatment alleviated feelings of helplessness in families. Vandagriff and colleagues’ (1992) study also found that providing accurate information for parents, and targeting parents of younger children for interventions to reduce stress and help them deal with parenting as well as management issues, was essential in order to ensure that these families could cope. Canam (1992) also suggests that health care professionals can make a difference in mediating stress by providing a supportive environment that fosters problem-solving abilities for parents in crisis situations.

One of the most stressful and fearful tasks facing parents of infants and toddlers with diabetes is meeting the crisis of hypoglycemic episodes. The crisis of these situations is documented in numerous studies reviewed for this discussion (Anderson et al., 1991; Banion et al., 1983; Betschart, 1988; Koski et al., 1991; Kovacs et al., 1991; Kushion et al., 1991; Lipman et al., 1989; Marteau et al., 1987; Puczynski et al., 1992; Rovet et al., 1988; Vandagriff et al., 1992; and Wysocki et al., 1989). With the young children involved in the current study this was described as the most frightening and challenging of all tasks. Parents described the sudden and unexpected onset, their own guilt over not recognizing early symptoms, and their ultimate relief in realizing that they did understand how to cope with the situation and could treat their child competently. Most parents’ first encounter with hypoglycemia in their child evoked instant panic, and parents were reminded of the vulnerability of their child. Calling someone for support following such incidents eased the parents’ stress and assured them that they had handled the situation adequately. However, for the parents of very young infants, it was sometimes necessary to seek medical advice or to hospitalize their child in cases of severe hypoglycemia. If it was impossible to feed their infant, seeking professional help was the only recourse available to parents. Although this was a suitable coping behaviour under the circumstances, hospitalizing the young child rekindled fears and anxieties, and left parents feeling inadequate, helpless and frustrated. Canam (1992) suggests that health care professionals should help parents to predict and to prepare for such stressful situations (p.8).
In order to avoid hypoglycemia, parents in the current study constantly monitored their children’s blood sugar levels, often during the night as well as before meals. They were also vigilant with mixing, measuring and administering their child’s insulin correctly. They used various tactics and strategies to ensure their child ate on time, and were in a constantly alert state of monitoring their child’s behaviour for any signs of hypoglycemia. Some parents reported sitting outside the door of the child’s playgroup because they were afraid teachers or attendants might miss a low blood sugar reaction in their child. Other parents slept with their child because of the fear of missing nocturnal hypoglycemia. These parents kept emergency supplies and glucagon at the bedside. Parents did not leave their child with anyone who could not perform a blood test or treat hypoglycemia. The honeymoon phase of diabetes was a difficult concept for parents to grasp, and during this phase of their experience parents lived in constant fear that their child’s own beta cells might suddenly produce too much insulin and lower the blood sugars dramatically. Few studies address this phenomenon except from a physiological point of view. To obtain reassurance, parents kept in constant touch with members of the diabetic management team for insulin changes and advice on management decisions.

**Making decisions**

During the early months of their experience, the process of making decisions about giving insulin or managing other facets of their child’s care was fraught with trepidation and emotion for parents in the current study. Parents did describe their ultimate decision to give the child’s insulin despite all the struggles and pain and sadness these procedures evoked. They also based their decisions to call health care professionals on the results of blood sugar readings which they had been taught how to interpret. Parents did describe feelings of guilt if their child’s blood sugar levels fluctuated too rapidly. For example some parents reported blood sugar fluctuations of from 25 mmoL/L to 2 mmoL/L in less than an hour. However, they felt utterly responsible for protecting their child from harm and, consequently, sought the advice of health care professionals. Parents described having difficulty about making decisions with regard to
disciplining their child and based this decision on blood sugar readings. All parents described their young
cild as requiring love, comfort and protection when their blood sugar levels created rapid mood swings,
irritability, or temper tantrums. Most parents admitted to overprotecting their child. Seeking help and
understanding from extended family or friends was not perceived as an easy task by the parents of the
young children in this study. Parents explained that finding a supportive individual with whom they could
talk about their concerns was difficult because most other people did not understand and were equally
afraid of the child’s precipitous situation. Some parents sought help from other parents with diabetic
youngsters. Most turned to health care professionals. The sixth developmental task outlined by Canam
(1992) suggests that parents must learn how to mange their own feelings, and that one of the most
important needs of parents is for health care professionals to attempt to better understand their problems
and to provide emotional support in a non-judgmental manner. Parents in this study described the need
to share responsibility with each other and with health care professionals.

Interacting with health care professionals

Parents’ interactions with health care professionals were deemed essential by all parents in the
current study. Parents relied implicitly on these experts for advice on managing their child’s diabetes.
Generally interactions were considered to be helpful and supportive to parents. However, sometime parents
expressed the opinion that not all experts truly understood the child’s or parents’ needs. In their study to
examine health care relationships from the chronic-illness perspective, Thorne and Robinson (1988)
described relationships between health care providers and health care recipients as evolving over time
through a process which has three identifiable stages (p.293). Combining the results of two previously
conducted qualitative research studies, these researchers described the alliance of family members with
health care professionals as progressing through the stages of "naive trusting", "disenchantment", and
"guarded alliance". The first stage was reported as being clearly described by family members early in
their experience with chronic illness. During this time family members began their health care relationships
implicitly trusting that health care professionals would act in the best interest of the chronically-ill child and family. They assumed that these professionals understood the families’ needs, and would collaborate and cooperate with family members in making mutually beneficial decisions. Later families identified discrepancies between the family members’ views and health care professional views. However, it took some time for parents to understand these different perspectives. In the second stage, Thorne and Robinson (1988) described some disenchantment on the part of family members as trust diminished and families perceived their sick child as vulnerable and in need of protection. During this stage family members required information in order to effect positive changes in their experience with the child’s illness; they looked for hope and understanding instead of simply technical advice as to necessary compliance with a treatment regimen. Although family members realized they had to have faith in someone in order to manage the chronic illness satisfactorily, they also sought empathy from health care professionals. However, parents often perceived this empathy as lacking. In the third stage “guarded alliance” was founded. At this time parents reconstructed their trust with health care professionals based on an informed rather than a naive level. Thorne and Robinson (1988) suggested that, during this stage, parents or family members had gained confidence and knowledge. They had the ability to handle their sick child’s need, and, although they remained vigilant in their approach to their child’s care, they could anticipate and manipulate certain situations. These researchers suggested that parents still experienced frustrations over what questions to ask health care professionals, but were also selective in the number of concerns or the amount of information they shared with these professionals over the long-term.

Parents in the current study could be described as passing through similar stages to those outlined by Thorne and Robinson (1988). In describing their interactions with health care professionals the parents described the implicit trust they initially felt during their child’s hospitalization. This trust in the opinions of health care providers and teachers led parents to implicitly believe that there was no flexibility or leeway in the child’s daily management regimen. Parents used the very specific instructions provided by
nurses, doctors and dietitians as the backbone for their very existence. This led to feelings of being totally trapped and irrevocably tied to their child’s schedule. Although the imposed regimen left parents feeling stressed, frustrated and exhausted they saw no way out. However, later on in their experience these same parents came to the realization that they could not implicitly follow all the imposed restrictions. They looked to health care professionals for empathy and understanding of their needs but, although they always received helpful and specific technical advice regarding their child’s management, the family’s emotional needs were not always met. Parents were often advised to seek the support of babysitters, but the means of obtaining these services was never suggested. Some parents in the study explained that they were always asked how their child’s blood sugar levels were, but not always how they were coping, or what their emotional needs were. Despite this, parents in the current study did acknowledge the absolute need for accurate technical advice, which was imperative to their child’s diabetic control and their own peace of mind.

Parents in this study also described their progression into the stage of "guarded alliance" as outlined by Thorne and Robinson (1988). Although this stage of interaction was not generally achieved until the parents in the study reached Phase Three of their experience, it will be discussed here as a continuum. During Phase Three, parents in this current study described how increased knowledge and understanding of their child’s condition had empowered them. They described the passage of time as having a healing effect. Although they maintained vigilance with their child’s management, these parents also new felt confident enough to manipulate the situation and make some decisions about their child’s care without consulting health care professionals. Often during the interviews the parents would explain their actions by first stating "I know they wouldn’t really approve at the diabetic clinic but this is what works for me". However, at no time during the current study did parents describe a lack of trust in health care professionals. They relied implicitly on the experts for advice on maintaining their infant’s or toddler’s diabetic control and subsequent growth and development. They also built a comfortable and
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trust a trusting relationship with the nurses and dietitians who had initially taught them in the hospital setting. They also acknowledged that, due to their high levels of stress at that time, they quite possibly did not comprehend all they had been taught about flexibility in their young child's regimen.

The intense need for empathy, understanding and someone to listen to their story was emphasized by the parents in this current study. The parents' need to talk and to understand each other's feelings, was described, as was the need for health care professionals to understand the family perspective. Parents viewed their inability to identify or understand each other's feelings as an impediment to coping and adapting. They described the interview process in this qualitative type of study as being a forum for sharing and understanding, and found this type of intervention most therapeutic and helpful. Based on the findings of this study, the current researcher advocates that a sharing, listening relationship should be fostered between health care professionals and families caring for a chronically-ill child. Thorne and Robinson (1988) advocate that understanding the family member's perspective of health care relationships is critical to the well being of the families (p.299). Kushion and colleagues (1991) also suggest that a team approach that is integrated and attends to the interaction of the child and family is essential. These authors advocate an alliance between parents and health care professionals. They suggest that regular education sessions with the clinical nurse specialist, in which parents receive updated information on management and development issues for the child, should be combined with support and active listening to the parents' articulated needs. Many authors acknowledge that parents must be allowed to collaborate with health care professionals, share experiences and to function as equal, essential, participating members of the health care team (Canam, 1992; Hatton, 1988; Metabolic Investigation Unit, 1986). In order to accomplish Canam's (1992) developmental tasks of managing their child's condition on a day-to-day basis, coping with ongoing stress and periodic crisis, assisting family members to manage their feelings and meeting the developmental needs of all family members, parents required a strong and trusting alliance with health care professionals.
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Identifying needs: reducing stress

Parents in the current study identified a number of sources that they perceived as having the potential to reduce stress. The availability and utilization of these sources determined the parents’ ability to cope with their child’s management and to meet their own needs. Parents described the need for empathy, understanding and support from others as paramount. They also identified a need for information and knowledge that could result in their better understanding of their child’s condition. They described the need for competence and empowerment. With these needs met, parents perceived a greater possibility of success in competently moving beyond mere survival tactics and better managing their situation. During this study parents repeatedly expressed the need to talk, and the need to listen to each other. They explained the helping nature of the interview process in allowing them to identify and clarify issues for themselves as well as for others. They described the need for someone to support and take care of them as parents and yearned for a helping relationship that showed concern for the entire family and not just for the child with diabetes. Parents in this study explained the need for health care professionals to better understand the complexity of caring for an infant or toddler with diabetes at home. They requested information on community resources, management updates, new devices to simplify procedures such as insulin injections, and information on parenting skills and developmental issues for the child. Within the first phase of their experience, parents had acknowledged an inability to identify their own needs or to understand their child’s needs. Now, within the second phase of their experience, parents were able to identify a variety of needs and resources to help them reduce stress and manage their child’s condition better.

The parents’ needs identified in this study were strongly supported in much of the literature reviewed by this researcher. Vandagriff and colleagues’ (1992) findings revealed that nurse clinicians or educators can assist parents by providing information on things that can be controlled, reassuring them about things that are difficult to control, reinforcing previously taught procedures or techniques in order
to move parents away from survival tactics to a more normal manner of coping and, in particular, encouraging parents to verbalize their fears and concerns. These researchers found that parents of younger children required more reinforcement of basic concepts of diabetic management as the child grows. They advised that these parents may require closer contact with health care providers in order to alleviate anxiety, and that regular phone calls from health care professionals to discuss concerns and give positive strokes for appropriate decision making will not foster dependence, but instead establish a nurturing, trusting relationship that encourages growth of the parents as well as of the child (p.301).

Betschart (1988) found that parents of children with diabetes had many feelings of guilt, inadequacy and stress that they were eager to share. This researcher recommended that health care professionals should listen and become aware of these feelings. In this way suitable support groups, increased education and more counselling services could be developed based on the parents' own needs and not the health care professionals' perception of the families' needs. Other researchers concluded that the parents of young children with diabetes have multiple needs and concerns that need to be addressed. They recommend that health care professionals should provide not only medical assessments but in-depth educational and psychosocial support. The availability of a twenty-four-hour telephone consultation service provides management flexibility, crisis intervention, and needed assurances for parents (Kushion et al., 1991; Lipman et al., 1989; Moyer, 1989).

Maintaining hope

Hope was not only an emotional response, it was a coping behaviour that motivated parents, and provided them with the impetus to maintain their child's health through vigilant adherence to the management regimen. Parents in this current study perceived their responsibility as one of keeping their child alive and well until a cure was found. Even parents who minimized the possibility of a cure looked toward better methods of treatment and less painful procedures to help their child in the future. The parents' hope was reinforced by research reports of new devices, new non-intrusive blood sugar testing
techniques and transplant advances. This hope, together with the passage of time and the parents' ever increasing ability to identify and meet their own needs led parents into the third phase of their articulated experience. No specific research articles pertaining to the concept of hope as a coping behaviour in the parents of young children with diabetes were reviewed. However, it is recommended by this researcher that further studies of the concept of hope as it pertains to parents of chronically-ill children should be undertaken.

Findings of this study have revealed that parents continue to experience multiple stressors during the early months following the diagnosis of diabetes in their young child. The pervasive nature of diabetes and the impact of the complex daily management was seen as contributing to an exacerbation of family stress and altered psychodynamics for the parents. Several articles pertaining to the experiences described by these families were reviewed. However, the limitations of these findings were considerable.

Some striking differences found in the current study compared to other findings were the complete involvement of fathers in the care and management of these children, the acceptance of frequent blood glucose testing by the infants and toddlers, and developmental issues related to the young age of the child which impacted significantly on the parents' ability to manage the complex regimen. Although parents initially described experiences of simply surviving and not really living, they did identify multiple needs and a number of sources they perceived as essential to reducing stress and helping them to competently manage the situation.

**Phase Three: Adapting over the Long Term**

For parents in this current study, the third phase of their experience began when they had learned to relax a little and to have faith in their own ability to parent a diabetic child. During this phase, most parents had acquired the confidence and flexibility to begin to trust and to teach others. Increased knowledge and understanding of their child's condition served to empower parents and enhance adaptation.
Most parents described this phase as less stressful and easier to manage than the early months following their child's diagnosis. They acknowledged major breakthroughs in their ability to cope and described a sudden realization that they had come a long way and felt more in control of the situation.

Parents also explained their transition into this phase as being related to time. They perceived time as a healer. Seeing their infant or toddler grow and develop normally despite the diabetes was a major factor that contributed towards the parents' ability to accept their child's condition. This time-bound concept seems to be congruent with the time-bound model of Fortier and Wanlass (1984) that suggests parents progress through sequential stages when coping with a child who has a chronic condition.

The first three stages of the Fortier and Wanlass (1984) model, termed "impact", "denial" and "grief", were compared to data from this current study during discussion of the child's diagnosis and hospitalization. The fourth stage of the Fortier and Wanlass (1984) model, termed "focusing outward", can be equated with findings from the current study during this third phase of the parents' experience. "Focusing outward" was described as being the stage during which parents demonstrate coping strategies appropriate to the situation. The parents begin to trust and accept help from others and begin to adapt to their life situation realistically (Fortier & Wanlass, 1984). Adapting to the situation also relates to the first adaptive task, presented in Canam's (1992) framework. In the current study, parents did describe the experience of new stressors and ongoing struggles. However, they also acknowledged an ability to take charge, be more flexible, maintain vigilance, teach others, trust others, build supports, achieve growth, manage stress with more confidence, and accept their child's condition. These acknowledged abilities are congruent with behaviours described by Fortier and Wanlass (1984). These researchers also identified a fifth time-bound stage they termed "closure". This was described as the final stage of the parents' experience. At this time, the parents accepted the disruption caused by their child's chronic condition and accommodated the child's needs into family life. Fortier and Wanlass (1984) also suggested that at this time, parents resolved the crisis that began with the initial "impact" stage. Although parents in the current
study described many of these fifth-stage behaviours, they still experienced recurring stress, frustration, anger, sadness, guilt, grief and depression when new problems or crises arose. Their young child’s diabetes also led to anticipatory worry on the part of parents who contemplated future events in their child’s life with fear and trepidation. Consequently, it would appear from the current findings that the concept of chronic sorrow researched by Clubb (1991) could also be further considered when discussing the current parents’ experience. The integrated model of Copley and Bodensteiner (1987), which proposes that emotional turmoil experienced by parents of a chronically-ill child may begin to fade but returns in a cyclical manner, can also be recognized in the parents’ experience described in this study. The adaptive task framework proposed by Canam (1992) can also be related to coping behaviours identified from the parents’ accounts.

During the following discussion, the parents’ experiences related to new stressors and ongoing struggles will be presented together with the parents’ reactions and responses to their situation. Common adaptive tasks facing parents of children with chronic conditions (Canam, 1992) will also be described as they relate to pertinent aspects of the parents’ adaptation process.

**Perceived Stressors and Parents’ Responses to the Situation**

Despite a perceived reduction in anxiety and stress for most families in the current study during this phase of their experience, recurring, new and ongoing struggles were vividly described by parents. Many of these stressors were significantly tied to developmental issues in the child.

**Developmental issues**

Findings in this study indicate that the young child’s growth and development had a significant impact on some of the problems related to the management regimen. During this third phase of the experience, parents did begin to feel more in control of their general situation. However, many of the facets of the required management became more complex due to the child’s developing cognitive and
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Physical abilities. Although parents perceived this maturation as being a positive development for the child, the new abilities, and the desire for independence in the toddler, caused different stresses and problems for the parents. Parents described issues surrounding blood testing, giving injections and confrontations over food as becoming more difficult due to a greater understanding on the part of the toddler, or an increased ability to resist. Although parents had anticipated that procedures such as giving insulin would become easier over time, this in fact was not always the case. As infants and young toddlers matured, they became physically stronger and protested more loudly. They were more difficult to restrain for injections, and this procedure often evoked cries of "don’t hurt me mommie." One family in this study was mistakenly accused of child abuse for restraining and hurting their child. This only reinforced the pervasive nature of diabetes and its required regimen, and contributed to new stress and recurring anger, guilt and frustration for the parents.

Confrontations over food also increased during this phase of the parents’ experience. Older toddlers were more aware of the variety of foods available and desired restricted foods. Some toddlers learned the significance of food and developed behaviours such as vomiting in order to manipulate their parents and gain attention. However, because of increased knowledge and an understanding of their child’s condition, parents did feel more in control. They did not experience the absolute panic that would have ensued in the early months following their child’s diagnosis, but instead allowed for some flexibility in the types of foods older toddlers were offered. Although parents acknowledged feeling more comfortable with handling such situations, they also explained that such problems would not have arisen when their toddler was younger, because the child was not smart enough to be manipulative. For toddlers who had been diagnosed after the age of two years, these age-related problems were reported earlier.

Because the child with diabetes was the first child for parents in all families but one in this study, knowledge about child development issues and how to handle them was limited. Kushion and colleagues (1991) stressed how important it was for parents of infants and toddlers with diabetes to understand
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normal development milestones in their child. They stressed the importance of minimizing the diabetes and encouraging normal growth and development. These authors suggested that parental stress and anxiety may be communicated and responded to by the child, and that the child may develop an unconscious need to be ill to keep the parents together or to reduce stress (p. 108). This could be related to behaviours such as the toddler learning to vomit because of the responses evoked in parents by such an act. Vandagriff and colleagues (1992) reported that parental anxiety may have a negative effect on the health status of a child with diabetes. These researchers suggested that overanxious family patterns such as overindulgence, overcontrolling, or overprotecting can affect the child's metabolic control, either directly through psychophysiological mechanisms such as stress arousal in the child, or indirectly by the instigation of behaviour problems surrounding food or insulin injections. In contrast, the longitudinal study by Kovacs and colleagues (1991) found that emotional distress in parents was not related to the diabetic child's metabolic control. Hauenstein and colleagues (1989) also reported no correlation between maternal stress scores and metabolic control for the child. Although the Vandagriff, Kovacs, and Hauenstein studies were related to children of all ages with diabetes, the contradictory findings of these researchers appear relevant to the parents caring for infants and toddlers in the current study. Although metabolic control in infants and toddlers is unstable and unpredictable, the overanxiety described by the parents could contribute to behaviour problems which in themselves could affect blood sugar control for the child.

Canam (1992) described the third adaptive task of parents with a chronically-ill child as being that of meeting the child's normal developmental needs. In order to accomplish this task, Canam suggested that parents must understand and focus on their child's developmental needs and not exclusively on the illness or disability. She suggests that children take cues from important adults in their lives, and if parents minimize the condition, so will the child. Parents in the current study were extremely anxious for their young child to develop normally. In fact, the ability to observe their child developing normally was a motivating factor to struggle on. Parents in this study also wanted their infant or toddler to be equal
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Many parents perceived their child as a normal toddler first, and as a diabetic second. They got very angry and frustrated if others didn’t see their diabetic child as normal. However, although diabetes is a "hidden" condition, physiological manifestations of the disease quickly surface if the daily regimen is not adhered to. The rigidity of the regimen imposes restrictions on the child and parents, and is a constant reminder of the presence of the disease. Consequently, health care professionals should understand the dilemma faced by the parents of diabetic toddlers. Trying to minimize the impact of the child’s condition and focusing on meeting the child’s normal development needs is an immense task faced the parents of diabetic children. Canam suggests that parents need to understand the importance of discipline in helping the child to develop a sense of security from having limits placed on their behaviour. Unfortunately, parents in this study were often stymied in their attempts to accomplish this task. Because of the difficulty in differentiating between normal toddler behaviour and diabetes-induced mood swings, some limitations were imposed on parents with regard to appropriate discipline for this young age group.

**Issues related to insulin injections**

A new problem associated with this third phase of the parents’ experience was related to the variable of time since diagnosis for the child, as well as the child’s development. The "honeymoon" or remission phase of diabetes often came to an end for infants and toddlers six months to a year post-diagnosis. Cessation of insulin production, combined with the rapid physical growth of the child, usually resulted in the need for a second insulin injection in the evening. Not only did the parents mourn the loss of their child’s endogenous insulin production, they were often faced with the loss of support systems they had just begun to build.

During this phase of their experience, parents in the current study had begun the process of teaching others about their child’s condition and had established a guarded or limited trust in selected family members or babysitters. These supportive individuals had learned how to perform blood tests, because this procedure was a non-traumatic event for infants and toddlers in this particular study.
However, none felt capable of taking on responsibility for giving insulin injections. Consequently, the threat of a second injection of insulin had major implications for the socialization of the parents and the child. Once again, "the monster called insulin" would disrupt the family lifestyle dramatically.

Grandparents who had previously been able to care for the diabetic youngster over the evening mealtime would no longer be able to do so, and fathers would be required to leave work earlier in order to participate in the insulin-giving procedure. Once again, family interaction and socialization patterns would be disrupted. This caused renewed stress and friction between parents. Although no research studies dealing directly with this problem have been found by this researcher, the need for education of extended family members and the need for renewed support and understanding of these parents’ concerns, is obvious (Clubb, 1991; Kushion, et al., 1991).

Because the stresses encountered by parents during this phase of their experience are inextricably tied to the coping behaviours or developmental tasks required to deal with these stressors, this discussion of the study findings will now examine some of the coping strategies adopted by the parents to manage their situation. Consequently, this section of Chapter Five will be organized somewhat differently from the format used to present the parents’ experiences in Chapter Four.

Coping Strategies Employed by Parents to Manage the Situation

Living with the problems associated with the trajectory of a young child’s diabetes gives rise to recurring feelings of anger, guilt, fear, frustration, anxiety, depression and resentment. These feeling states are experienced by both parents and extended family members, and can be evoked by recurring crisis or by struggles and disappointments surrounding establishing support systems.

Managing stress and worry

One of the most difficult tasks for parents in this study was coping with their own worries, while at the same time understanding their partners’ worries, and the concerns of other members of the family.
Canam's (1992) common adaptive tasks of "meeting the developmental needs of all family members", "coping with ongoing stress and periodic crisis", and "assisting family members to manage their feelings" are all tasks faced by parents in the current study.

For meeting the developmental needs of all family members, Canam (1992) suggests that parents of chronically-ill children need to preserve family relationships, maintain strong marital ties and also meet their own needs. Continual focus on the child's needs at the expense of other family members' needs can lead to dysfunctional family relationships. Canam (1992) further suggested that flexibility and not rigidity is needed, and a willingness to share responsibilities within the family is a positive coping behaviour (p. 6). Parents in the current study identified their own need to grow as individuals. Sometimes they described different types of worry, such as fathers' worries about maintaining their job in order to support the family, and mothers' worries about confrontations with their toddlers over injections and food. The constant worry of both parents about managing their child's diabetes and controlling blood sugar levels was often complicated due to differences in attitude and expectations of parents. The ability to deal with these differences was a difficult task for the parents of these young infants and toddlers to accomplish.

To cope with ongoing stress and periodic crisis, Canam's (1992) framework suggests that problem-solving ability to clarify issues, and efforts to decrease the emotional reaction of all family members, may also help parents to feel less stress and provide hope (p. 7). In assisting family members to manage their feelings, Canam (1992) also suggests parents should find a supportive individual with whom they can talk over their concerns.

**Sharing; talking (hidden benefit of study)**

One of the hidden or unanticipated benefits of this current study process was the therapeutic results achieved by parents who were encouraged to talk and share their concerns and perceptions during the taped interviews. Some parents revealed how little they had known about the other's feelings and how lack of understanding of the other's worries led to conflict. During the interview process of the study,
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some fathers shared experiences of how they helped their infant or toddler accept insulin injections. Mothers had been totally unaware of the fathers’ methods. Other parents explained how little they had previously understood about the changes that had occurred in their relationships since their young child’s diagnosis. They explained how talking things out together had helped to put everything into perspective. All parents in the current study explained the benefits of having someone listen to their story. Being able to talk and have someone to actively listen was described as a coping behaviour that could reduce stress and increase understanding of the other parent’s needs and concerns. These findings are congruent with Canam’s (1992) suggested adaptive task, that recommends parents of chronically-ill children should seek health care professionals or other parents in similar situations to obtain this type of supportive relationship. Having a health care professional listen to their concerns with the sole purpose of understanding their experiences and needs better was perceived as extremely beneficial for all parents in the current study.

Emotional support received from other parents with young diabetic children was also appreciated by families in the current study. Some parents described the support from other mothers experiencing similar problems as being more helpful than support from extended families, because these mothers understood the situation. However, parents sometimes found the advice of parents with older diabetic children as being negative and depressing. The advantages and disadvantages of support groups for children with long-term conditions is well-documented in the literature (Betschart, 1988; Clubb, 1991; Phillips, 1990; and Rawlins & Horner, 1988). Rawlins and Horner (1988) suggest that nursing can play an integral role in the design and implementation of support groups for parents of chronically-ill children. Their research showed that the therapeutic importance of parent-to-parent support groups should not be underestimated, and that, ultimately, this type of support can relieve some of the negative feelings associated with parenting a chronically-ill child (p. 406). The need for a support group specifically formed for parents of young children with diabetes was requested by families in the current study. Each family felt isolated because of the limited population of parents caring for such young children, and each
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expressed the need to share experiences with other parents dealing with the unique needs of infants and toddlers.

Teaching and trusting others

For parents of these very young diabetic children, the amount of trust they could have in other caretakers was directly related to the amount of information and teaching they could provide for relatives or babysitters. During this third phase of their experience, most parents had acquired the ability and confidence to manipulate and experiment a little with their infant's or toddler's diet or insulin requirements. However, despite confidence in their own abilities, parents did not expect other caregivers to attempt such flexibility. Indeed, in order to trust others with their child's care, parents in the current study expected caregivers to demonstrate anxiety and vigilance with regard to the infant's or toddler's diabetic regimen. One of the parents' major concerns about leaving their young child was the other caregivers' competency in handling hypoglycemic episodes. When explaining their methods of selecting babysitters or alternative caregivers, parents in this study expressed concern about the enormity of the responsibility placed upon the other person. These parents felt impelled to select caregivers whom they had taught to perform blood tests, and those who could analyze and interpret the results competently.

One of the major tasks undertaken by the parents in this study was to instruct other caregivers on how to recognize and treat hypoglycemia. Even parents who accepted their child's diabetes as "no big deal" explained the implicit instructions they left with any babysitter. Parents who returned to work only felt comfortable leaving their child with caregivers whom they had taught themselves. Each family explained that they could only trust those who had shown an ability to test blood sugar levels and handle hypoglycemia.

Teaching and trusting others was a requirement for these families before establishing of support systems was accomplished. Canam's (1992) seventh adaptive task for parents of chronically-ill children is described as educating others about the child's condition. Canam (1992) explained that the task of
parents is not only to gain an accurate and complete understanding of their child's condition themselves, but also to educate others, including siblings, extended family members, friends, neighbours and other care providers. Because an infant or toddler with diabetes cannot understand, or in any way express, his or her own feelings or needs, accomplishment of this task is imperative. For parents, establishing support is inextricably tied to the task of teaching and trusting others.

**Building supports**

Many parents in the current study explained how time had healed and eased some of the fears of grandparents and other extended family members. Parents had also started to trust those whom they had taught, and had begun to utilize these human resources as support. However, some extended family members had not adapted well, were still unable to perform blood tests, and often increased the parents' stress by negative behaviours. Because parents themselves were still fearful of hypoglycemia, they were cognizant of the fears of others. Consequently, they realized that building support systems would be a challenge, and a task constantly fraught by realization of the enormity of their child's needs. Canam's (1992) framework suggests that the task of establishing a support system is imperative if parents are to cope effectively with a child's chronic condition. This researcher recommends that families should acquire support through health care professionals, community resources, extended family, other parents of children with chronic conditions, and friends. Because of the inordinate amount of time and energy spent by parents in coping with the demands of an infant or toddler with diabetes, little energy is left for actively seeking the support needed for themselves. Most of the literature researched for this discussion indicates the important role of health care providers in assisting parents to establish support. The role of the clinical nurse specialist in initiating support for families was stressed (Moyer, 1989).

**Growing as a family**

The need to promote self-esteem in all family members and to meet the needs of parents for growth and development was described by Canam (1992) as part of the fourth adaptive task of meeting
the developmental needs of all family members. In the current study, parents described their need to move away from the holding pattern of just surviving, and to begin the task of putting their lives back together again. During this third stage of their experience, parents described a sudden realization that some of their depression had lifted, that the intense emotional turmoil of the first two phases of their experience had eased, and that at times they could even forget their child’s diabetes and feel happy and enjoy life again. Knowledge, a new understanding of the child’s condition, and confidence in their own abilities enhanced adaptation. Seeing their young child develop normally despite the horrendous and rigid management regimen contributed to the parents’ feelings of satisfaction and accomplishment. However, these parents lived a constant paradox. While attempting to achieve normality for their child and for themselves, they were constantly faced with dilemma of sacrificing some of the vigilance required to maintain adequate control for the infant or toddler. The families’ continuing struggle with this dichotomy created feelings of ambivalence. No studies directly related to this problem for the families of young children with diabetes were reviewed by this researcher. However, it is an area of concern that should be researched further by health care professionals, so that appropriate interventions can be established for the families.

**Anticipatory worry**

Due to the pervasive nature of diabetes and the enormity of the task of caring for these infants and toddlers, the parents identified major anxieties and fear that reflected their deep commitment to guarding their child’s health and future survival.

As parents contemplated their young child’s multiple and complex needs, they also began to anticipate and worry about events or situations that could arise to threaten their child’s safety and survival. Parents described feelings of panic which were precipitated by a fear of the child getting lost and being too young to adequately explain his or her own needs. Parents experienced the intense anticipated fear of their child dying of a hypoglycemic seizure because other caregivers, teachers or strangers did not understand the ramifications of diabetes. This fear appeared to be induced by the parents’ feelings of total
responsibility for their child's very existence and future well-being. The anticipation of the young child entering pre-school or kindergarten also evoked these feelings of panic. Although most of the studies reviewed for this discussion suggest that the fear of hypoglycemia is a major stressor for parents (Banion et al., 1983; Betschart, 1988; Kovacs et al., 1991; Lipman et al., 1989; Marteau et al., 1987; Vandagriff et al., 1992), few suggest interventions to help alleviate these fears. A longitudinal study to find out how parents of infants or toddlers manage these fears and worries, as the child grows older and becomes more independent, is indicated. Because of these anticipated worries, parents also described their reactions to the prospect of having another child.

Decisions to have other children

In retrospect, this current study might have been unique in that all but one of the infants and toddlers with diabetes were the first child in the family. Consequently, because of the young age of the child, the possibility of the parents having further children was increased. For these families, the diagnosis of diabetes in their child had definite but often different implications for parents when they were making decisions about having other children. For some parents, the initial idea of having another child was to replace the less-than-perfect infant or toddler who now had diabetes. For others, the plan was to provide a companion for their diabetic youngster. Some parents questioned their ability to care for another child in light of the overwhelming situation of caring for a toddler with diabetes. Many parents described their experience as one of already caring for two children, the infant or toddler being the first child and the diabetes being the second. They had difficulty with the concept of sharing their love and attention between their diabetic youngster who had so many needs, and a new baby. Most felt they would have trouble handling the situation. Nonetheless, two families did have another infant during the course of the study, and one mother became pregnant. However, each of these families continued to express concerns about handling another child. Two families had made the decision not to have another child because of
their fear that a second child could develop diabetes, and each family voiced some concerns about the prospect of a second child developing diabetes. Two mothers expressed sorrow for the new baby in the family, because that child would receive less love and attention than the diabetic youngster. Other parents anticipated hypoglycemic episodes in their diabetic toddler and worried about how they would cope with that while at the same time trying to meet the needs of another infant or toddler.

The impact of their first child’s diabetes had significant implications for all parents. Each family worried that diminished parental attention could result in loss of metabolic control and threaten the future health of their diabetic child. Although no studies reviewed by this researcher discussed the implications of having another infant in the family, many researchers did report on the inordinate amount of stress and anxiety experienced by the parents of a young diabetic child. Several studies indicated that the mother is the person most involved with the coordination of daily care for the chronically-ill child (Banion et al., 1983; Chan & Leff, 1982; Freeman, 1984). These authors also suggest that, because the mother is so intimately bound to the details of the child’s illness, any problems that she has coping with the daily management regimen may affect the entire family. Henderson and Thompson (1992) reported that invasive and painful procedures for an infant or toddler, combined with loss of support systems and recurring guilt and grief, could affect a parent’s ability to function effectively and had implications for the diabetic child and any siblings. Lorenze (1991) and LaGreca (1991) reported that diabetes in a child requires a high degree of parental involvement, and that the demands of insulin injections, blood testing, dietary management and maintaining blood sugar control demands both parents’ involvement and energy. These researchers suggested that, during early childhood, parents must assume total responsibility for the child’s care. Anderson and colleagues (1991) report that, with very young children, shared responsibility and open communication between both parents is an important factor in achieving maximum metabolic control for the child. Although the mother-child dyad was emphasized in most studies, psychological stress, including symptoms of anxiety, somatization, dysphoria and total exhaustion was reported in both
parents of infants and toddlers with diabetes (Koski et al., 1991; Kovacs et al., 1991). Because the overall and ultimate commitment of all the parents in this current study was to ensure that their infant or toddler with diabetes survived and was adequately cared for, it does not seem surprising that families contemplated the responsibility of managing another young infant with concern and trepidation. The enormity of the task of managing the complexity of this unpredictable health problem in one young child could be perceived as a full-time occupation for both parents.

Summary

This chapter has discussed the findings of the current study in relation to other authors' published work on the topic. Both experiential and research-based articles were compared to the study findings. However, when possible, empirical data which either supported or refuted specific findings in the study was emphasized.

Several recently published articles pertaining to the study content were identified. However, the limitations of these findings were considerable, and there remains a paucity of research literature specifically directed towards the study of parents' perceptions of caring for an infant or toddler with diabetes. Many studies were limited to the experiences of mothers only, whereas in this current study the experiences of fathers were equally emphasized. In general, most of the studies directed towards care of a child with diabetes focused on the older child. Consequently, because of limitations of published articles on developmental issues pertaining to infants and toddlers with diabetes, this chapter also included more general literature pertaining to developmental issues in the chronically-ill child.

The findings of this study clearly suggest that parents of infants and toddlers with diabetes experience inordinate amounts of stress as they struggle to manage the complex daily regimen. The young age of the child, and the child's inability to recognize their own needs or accept any responsibility for their
own care place an extra burden of responsibility on the parents. Feelings of being totally responsible for their child’s life and very existence are paramount for these parents.

Developmental issues which impact significantly on the management regimen, the young child’s acceptance of painful, invasive procedures, metabolic control, and socialization patterns of the family appear limited to this unique population of diabetic children and their parents. The pervasive nature of diabetes is seen as contributing to an exacerbation of family stress and altered psychodynamics for the parents of these infants and toddlers. Recently published articles on "Issues in the care of infants and toddlers with diabetes", by Kushion and colleagues (1991), and "What parents of children with diabetes are worried about" by Vandagriff and colleagues (1992), lend credence to most of the findings in this study.

General literature relating to children of all ages with chronic illnesses lends support to many of the findings regarding stressors, the parents’ responses to these stressors, and the coping behaviours employed by the parents to manage their situation. The concepts of time-bound models and the chronic sorrow phenomenon help to identify emotional responses of parents as they pertained to the three conceptualized phases of the parents’ experience in the current study. The three phases are found to be congruent with an integrated model which embodies characteristics of both the time-bound and chronic sorrow concepts. A framework of adaptive tasks proposed by Canam (1992) also helps explore parents’ coping abilities in all three phases of the parents’ experience.

Several striking differences were found in the current study data compared to findings in the literature. One difference was the complete involvement of fathers in the care and management of these infants and toddlers, and the report of parents that a stronger bond was forged between fathers and their young child following the diagnosis of diabetes. This finding was contrary to that of other studies that generally reported fathers as assuming an instrumental role in the care of chronically-ill children. Studies that reported a special bond in the relationship between a mother and the chronically-ill child were
disputed in this study. Mothers felt alienated from their young children due to the constant emotional turmoil over painful, intrusive procedures. A second difference was that the loss of flexibility, spontaneity and freedom were accentuated in this population, which resulted in social isolation. The younger the child, the greater the loneliness experienced by parents. Social isolation was exacerbated by the parents’ difficulty in trusting others, and extended family members’ fear of the complex needs of the child.

Another striking difference in this study, which refuted findings in the literature, was the acceptance by infants and toddlers of the painful, intrusive procedure of blood glucose testing. However, the struggles and frustrations of insulin injections were congruent with the fears of toddlers concerning any painful procedures.

With regard to developmental issues, toddlers who had been diagnosed after the age of two regressed in psychomotor development, whereas infants diagnosed during the first months of life were reported by parents to be advanced both cognitively and physically. No documented evidence in the literature could be found to support or refute these findings.

Other findings concerning anticipatory worry, the parents’ decisions to have more children, and developmental issues related to the passage of time and the "honeymoon" or remission phase of diabetes and diabetic management, all appeared to be relatively unique to this population. However, because no previous studies have been conducted to elicit the experiences of parents who are caring for an infant or toddler with diabetes, no literature was found to support or refute these findings. Generally, the findings of this study supported other findings related to care of chronically-ill children, and in particular, care of children with diabetes. However a number of new and interesting questions about this special population have emerged from the findings of this study.
Summary

This study was designed to explore parents’ perceptions of their day-to-day lived experience of caring for an infant or toddler under three years with insulin dependent diabetes mellitus. Impetus for the study was initiated by questions and concerns and a need for understanding that arose from the observations made by the researcher during clinical nursing practice. Little has been written about caring for an infant or toddler with diabetes, and no previous study has been found that addressed the topic from the parents’ perspective. Therefore, this study differs from others in its methodology and focus.

The methodology that directed this study was the phenomenological paradigm of qualitative research and theory. This methodology provides an approach whereby the researcher can gain in-depth understanding of the parents’ perspective of caring for a young child under three years with insulin-dependent diabetes mellitus. This type of research involves methods whereby characteristics, attributes and meanings of the phenomenon under study are identified, documented and interpreted. These designs are typically used when little is known about a phenomenon. The task of the method is to investigate and describe the human experience. The objective of the study method is to "paint a picture" that increases understanding of the parents’ perceived experience and to help the reader "walk a mile in the parents’ shoes." The informants’ accounts are constructed and organized into common or unifying themes that describe the phenomenon from the parents’ point of view.

The conceptual framework chosen to guide this study was developed by Kleinman (1978) through work in the area of cross-cultural medicine. Kleinman conceptualized the health care system as being comprised of three different but interacting sectors, each with their own explanatory model of health and illness. The three interacting sectors are referred to as the professional, the popular and the folk arenas.
Each arena is viewed as a sociocultural system with its own beliefs, values, norms, and its own explanatory model of health and illness. For the purpose of this study, the domain of inquiry was the popular arena, which comprises principally the family context of sickness and care. This arena encompasses beliefs, choices, decisions, roles, relationships and interactions, and includes the parents' subjective experience of their infant's or toddler's long-term illness of diabetes, and their perceptions of caring for the child on a day-to-day basis. The parents' explanatory model is not necessarily congruent with the health care professionals' model.

Literature related to the topic was reviewed in order to provide a background to the study. Only a few studies were available on the chosen research topic, and there were no studies identified by the researcher which specifically described the lived experience of parents caring for a young child under three years with diabetes. However, several bodies of literature from areas that were relevant and linked to the identified problem and purpose of the study were reviewed. Both experiential and research-based articles were examined in order to, first, provide a broad overview of the impact of a child's chronic long-term illness on the child, the parents and the family, second, to identify the impact of diabetes in children on the parents and family, and third, to review the unique needs and problems associated with caring for an infant or toddler with diabetes. It was apparent from the literature review that little is known about the parents' perceptions of their experience of caring for such young children on a day-to-day basis. The literature review was guided by the conceptual framework.

Data were collected through in-depth interviews conducted with eight families. Eight mothers and five fathers from these families participated in the interviews, which were audiotaped. Verbatim transcripts of the taped interviews were analyzed. Field notes were kept. Data collection and data analysis occurred simultaneously through the process of constant comparative analysis. A final analysis was done following completion of the last interview. The data were constructed through a series of 14 interviews conducted over a five-month period. During this time, data were categorized and clustered into related
concepts and themes. The final stage of analysis brought together and confirmed all previously developed ideas. Throughout the study, the researcher utilized the techniques of bracketing and reduction in order to perceive the phenomenon from the participants' vantage point. Auditability and confirmability were used as criteria of rigour for achieving credibility and ensuring the truth, value and applicability of data (Sandelowski, 1986, p. 35).

The parents' accounts were organized into three distinct phases. The first phase began when the infant or toddler was diagnosed with diabetes and was admitted to hospital. This was termed the diagnosis or initial crisis phase. The second phase began when the infant or toddler was discharged from hospital and the parents began the task of caring for their young child with diabetes at home. The third phase was related to the process of adapting and incorporating the infant's or toddler's diabetic regimen into family life over the long term. The three distinct phases were linked to a timeframe and a series of events occurring in the parents' lives, and provided a structural framework for the conceptual categories and themes that were organized from significant statements made by parents during the interviewing process.

Three major conceptual categories identified from the parents' accounts described perceived stressors, the families' reactions and responses to these perceived stressors, and coping strategies employed by parents to manage their situation. These three conceptual categories were used as a structure for presenting the themes in all three phases of the parents' described experiences. Significant statements were extracted from each parent's story and regrouped into themes which were composites of data from the combined experiences of all families in the study. Each theme was organized under one of the major conceptual categories and then placed within the appropriate phase of the parents' experience. Because the three phases of the experience occurred on a continuum, several prominent themes persisted to one degree or another throughout the three phases. When the themes and concepts were presented, verbatim quotes from the parents' accounts were used to explain and enrich the findings.
The findings of this study were related to the findings of a variety of both experiential and research-based articles. An in-depth exploration of literature specifically related to the phases, conceptual categories, and themes developed from analysis of the data was provided. Literature that confirmed or refuted the current study findings was presented. Findings of this study supported much of the information reported in the literature. However, several of this study's findings reflect themes that have not previously emerged from the literature, and therefore warrant further exploration.

**Significant Conclusions from Findings**

The following significant conclusions from the study findings will be listed and then discussed.

1. Families go through three distinct phases in their experience of caring for an infant or toddler under three years with insulin dependent diabetes. However, some stressors recur on a continuum throughout each phase of the experience.

2. Parents and extended family members respond to the young child’s diagnosis and management according to their own values, beliefs, prior experiences with diabetes or other long-term illnesses, and other stressors in their lives.

3. The critical nature of the young child’s condition at diagnosis has a profound effect on the parents’ ability to cope.

4. Parents of infants and toddlers with diabetes experience multiple losses in their lives. These losses result from the rigid and complex management regimen that impacts on every facet of the child's and parents' life. Parents also mourn future losses for their child.

5. Developmental issues in the young child impact significantly on the management regimen and the parents’ ability to achieve good diabetic control for the child.

6. Major lifestyle changes are required by families caring for a young child with diabetes.

7. Fathers play a significant role in the custodial care of the young diabetic child.
8. Implications for developing a reliable, non-invasive blood monitoring device are significantly increased due to the needs of this growing population of infants and toddlers. Parents and health care professionals rely implicitly on blood glucose monitoring as a way of understanding the young child’s needs.

9. The interview process was a therapeutic and valuable forum for parents in which they shared information and began to understand each other’s needs.

Conclusions and Implications for Nursing Practice

The first six conclusions about the findings of this study will now be presented in more detail and the implications for nursing practice which evolve from these conclusions will be described. Nurses working with the families of infants and toddlers diagnosed with diabetes should become implicitly aware of the widespread implications and pervasive influence that this lifelong condition can have on the life of the child and the entire family, not only at the initial onset of the disease but through continuing phases of the family’s experience.

A major conclusion of this study is that families go through three distinct phases in their experience of caring for an infant or toddler under three years with insulin dependent diabetes. As well documented in the findings of this study, these three phases follow a timeframe, and identify vulnerable times in the parents’ lives that require nursing interventions directed towards helping the parents to adapt. Health care professionals should be cognizant of the specific stressors and needs of parents as they progress through each phase of their experience, so that appropriate support, education and advocacy can be provided. The first phase of the parents’ experience encompasses the initial crisis related to the diagnosis and hospitalization of the young child. The second phase began when the infant or toddler was discharged from hospital and the parents began the task of caring for the young diabetic child at home.
The third phase was related to the process of adaptation and managing the child's condition over the long term. Parents described each phase as having its own stressors and struggles that required management. However, some stressors and crisis situations recurred or were sustained on a continuum throughout each phase of the parents' experience. Rekindling of intense anxiety, fear and frustration occurred with each new crisis faced by parents in the trajectory of their young child's illness. Consequently, while acknowledging a time-bound sequence of adaptation behaviours, health care professionals should also be aware of potential crisis for families through the phases.

The second conclusion drawn from this study's findings is that parents respond to their young child's diagnosis and long-term chronic illness according to their own values, beliefs and prior experiences with diabetes or other long-term illnesses. This conclusion also extends to the responses of extended family members to the child's diabetes and the support these individuals provide. The number of stressors already impacting on the parents' lives prior to the young child's diagnosis were also reflected in the parents' perception of their situation and acceptance of it. This multifaceted conclusion is based on Kleinman's (1978) health care system's explanatory model that was used as a conceptual framework for this study. McCubbin's (1982) framework that outlines a pile up of multiple stressors impacting on parents' lives was also used to guide the compiling of data that supports this second conclusion.

This conclusion implies that major differences will result in the parents' handling of their situation, and that these differences in perception will impact significantly on the interactions between parents and health care professionals. The explanatory models of illness and health are experientially based for parents, and serve to give meaning and direction to the family's behaviour both during the child's initial hospitalization and over the long term. Although it should be common knowledge among nurses and other health care professionals that parents do react to a child's long-term illness in different ways, much of the assessment of family needs, and information provided for parents, is still focused on the health care professionals' perspective. Even awareness of the differences in the parents' perspective is not necessarily
Parents' Perceptions of Caring for Infant Diabetes

sufficient to ensure that the health care provided will meet the perceived needs of the parent or child. Because diabetes requires a medically oriented and complex management regimen for the child, it is imperative for health care professionals to understand that parents may not view this regimen in the same way as they do. It is necessary for parents and health care professionals to negotiate on a common ground of understanding. Nurses should collaborate with parents, formulate a mutually acceptable plan for the infant’s or toddler’s care, and work within the confines and acceptance of the parents’ belief system. Understanding the perspective of extended family members and the availability of support from these significant individuals would also help health care professionals to provide adequate support and nurturing for these families. One way this can be accomplished is for health care professionals to elicit the parents’ point of view. Actively listening to the parents, and then providing information in a manner that is relevant to the parents’ belief system and ability to manage the situation, is recommended.

Diabetes in such a young child dictates that parents assume full responsibility for the child’s life and very survival. They have little choice in the matter of managing the crucial day-to-day regimen. These parents require support and the ability to share responsibility with health care professionals. Consequently, building a mutually respecting and trusting relationship is essential. Because nurses in particular have the mandate to teach, support and work with these families over the long term, it is important for them to guard against the expectation that parents will view their child’s condition and needs from a health care professional’s perspective. Nuturing and caring for the parents as well as the child should also constitute an essential element of the nurses mandate.

The third conclusion drawn from the findings of this study is that the critical nature of the young child’s diabetes at the time of diagnosis has a profound effect on the parents’ ability to cope. The magnitude of the parents’ stress at the diagnosis is exacerbated by the hospital experience, and the need for painful intrusive procedures performed so frequently. The shock, disbelief, fear, and anxiety is
increased when parents realize that they will be expected to continue with these same painful procedures over the long term at home.

Health care professionals should understand that few chronic long-term conditions begin so abruptly and acutely in a previously healthy infant or toddler. Because the child is so critically ill when hospitalized, health care professionals are committed to saving the child’s life and restoring metabolic control. Although each is aware of the impact of these life-saving procedures on the parent of the child, few realize the effect this experience has on the parents when they are faced with learning about the complexities of the regimen soon after the child’s condition is stabilized. Health care professionals should become acutely aware of the disruption, disorganization and disequilibrium experienced by the parents. Utter exhaustion, combined with acute stress, creates a condition of shock and denial that may be manifested in robot-like behaviour. Parents may also direct anger towards health care professionals, or may feel the need to be assertive and advocate for their child. Empathy and support is imperative for these parents. Because nurses have the mandate and responsibility to teach these parents the painful, intrusive procedures required by the child, special empathy and trust should be established between the nurse and the family. The role of a nurse clinician or clinical nurse specialist in meeting the needs of these families is stressed in the literature. Parents in this current study also implied that the stressful hospital environment was not the best place for parents to learn. Instead, once basic survival skills had been acquired, they suggested that the rest of the teaching/learning process should take place in the home environment. This has major implications for nursing practice. A community outreach teaching program would be cost-effective because of a reduced hospital stay for the child. However, education of more nurses to accommodate community-based teaching programs would be necessary.

A fourth conclusion is that parents of infants and toddlers with diabetes experience many losses in their lives, including loss of flexibility, loss of spontaneity, loss of freedom, loss of support systems
Parents' Perceptions of Caring for Infant Diabetes

and intangible losses that are difficult for parents to describe. These losses result from the rigid and complex management regimen that impacts on every facet of the child’s and parent’s life. Due to the inordinate amount of time parents spend on caring for their young diabetic child, they feel trapped and unable to form social networks. Due to their own intense fear of hypoglycemia, parents have difficulty trusting others with care of their child. Extended family members and babysitters share the parents’ fear and are reluctant to accept responsibility for the child’s management. This loss of support systems results in social isolation for the parents. From the study findings it appeared that the younger the child at diagnosis, the greater the loneliness and social isolation experienced. Although parents attempted to teach others how to perform blood tests, and how to treat hypoglycemia in the child, informing others was a difficult task.

Nurses and other health care professionals should be cognizant of the fact that social isolation, loss of support systems and parents’ difficulties with trusting others are all related to the impact of the child’s diabetes on daily living, and the realities of managing the complex and demanding regimen. Families in the study cited incidents in which health care professionals suggested they should get a babysitter and go out, without realizing the difficulties parents had in obtaining such support. Implications for nursing practice are multiple. The organizing and implementing of support groups and babysitting services for these families should form part of the nursing mandate. Providing or recommending respite services and providing education for grandparents, babysitters, or other caregivers would meet the needs of many of these families. Education to reduce the fear and stress in other significant individuals, and providing them with the confidence to take on responsibility for a diabetic child, is indicated. Providing parents with the confidence to trust others, and explaining ways in which parents can achieve flexibility without sacrificing vigilance in their child’s management regimen, should form part of the ongoing nursing care and management of these families. Developing a community network of supporters should be a nursing goal.
Parents in this study also wistfully mourned the many losses their young diabetic child would experience in the future. Grieving over lost opportunities for their child led to feelings of guilt and depression in many parents. Providing support, listening to the parents’ fears and helping them to look positively on their child’s future should form an integral part of nursing care for these families.

The fifth conclusion drawn from the findings of this study is that developmental issues in the child impact significantly on the management regimen and the parents’ ability to achieve good diabetic control for the child. The infant’s and toddler’s inability to recognize or identify their own needs means that parents must anticipate and take full responsibility for the child’s care. A diminished ability to communicate and cooperate with the treatment regimen leads to struggles and confrontations which cause stress for the parents. The altered physiology of the child and lability of blood sugar levels contributes to rapid mood swings and sudden and frightening episodes of hypoglycemia. Also, because most of the children in the study were the family’s first child, parents had limited knowledge of developmental milestones, and had difficulty differentiating between normal infant or toddler behaviour and diabetes-related behaviour.

Implications for nursing practice include a nursing mandate to teach parents about developmental milestones for infants and toddlers, to provide information on parenting skills and how to manage manipulative behaviour and to assist parents in differentiating between normal toddler behaviour and diabetes induced mood swings. Reinforcing the physiological changes in a young diabetic child so that parents could better understand and control fluctuating blood sugar levels would reduce stress and enhance adaptation for these families. Linking parents to other families who have successfully managed a young child with diabetes could also provide much needed support and encouragement for these parents.

The sixth conclusion of this study is that major lifestyle changes are required in families caring for a young child with diabetes. However, empowering parents by providing them with the knowledge and skills to competently manage their child’s condition and incorporate the complex needs into an
acceptable and comfortable lifestyle is a crucial element of the nurse’s responsibility. Listening to parents, identifying needs based on the parents’ articulated experiences, and offering appropriate support, information, and ongoing education is a major area of nursing intervention. Parents in this study identified nurses as a primary support system. Consequently, the mandate to establish a relationship in which information is shared, based on the developmental needs of both the child and the family, is crucial for the nurse clinician or practitioner.

The seventh conclusion drawn from the findings of this study will be discussed in the following section as it relates to implications for nursing research. The eighth conclusion will be discussed in the final section of this chapter as it has implications for both nursing and technological research.

The ninth conclusion emerged as a hidden or unanticipated benefit of this study. Parents described the interview process itself as therapeutic. They found telling their own story and having someone to listen to them was most beneficial. When both parents participated they shared experiences, and consequently better understood each other’s needs. This implies that empathetic listening on the part of nurses could be of inordinate benefit to families. It could promote mutual trust and also provide nurses with indepth understanding of the parent’s concerns and needs.

Implications for Nursing Research

This study has demonstrated that in-depth exploration of the parents’ perspective of their experiences of caring for an infant or toddler with diabetes provides valuable insight and a greater understanding of this phenomenon. However, because the study was conducted with such a limited number of parents, whose children were all followed by the same multidisciplinary team at a large tertiary care facility, more studies of this unique and growing population being cared for in other situations is indicated. From the findings, it can be concluded that this population of young diabetic children and their parents experience several stressors and identify multiple needs that are quite different from those of
families with older diabetic children. These stressors are not always understood by health care professionals, and the families’ needs are not always met adequately. More studies to confirm or refute the findings in this study are indicated. Many authors and researchers whose work was reviewed and quoted during the process of constructing this thesis indicate that more qualitative type studies that provide insight into the experience from the parents’ perspective are required. Findings of this study support these authors’ and researchers’ recommendations.

Several studies reviewed for this thesis indicate that the mother is the person most involved with coordinating the care of the chronically-ill child. Most previous studies have only elicited the experiences of mothers, and consequently address only the mother’s role and coping behaviours. Most studies report that in general, the father assumes primarily an instrumental role in the care of chronically-ill children. A striking difference indicated by this current study data shows that fathers are intimately involved in the custodial care of their young diabetic child, and are relied upon implicitly to undertake many of the procedures required in the complex management regimen. This study indicates that fathers’ socialization patterns are changed dramatically due to the necessity for them to participate in the child’s regimen. It also indicates that a stronger bond in the relationship between the father and the young diabetic child is forged due to the father’s total commitment to and involvement in the child’s care. A possible reason for this finding is the changing role of fathers in today’s society and the expectation that fathers become more involved in their young child’s care. It is also possible that the fathers participating in this study were unique and their behaviours could not be generalized to other situations or families with chronically ill children. Because of these findings, more studies of the father’s perspective and the father’s role in caring for such young children who require a complex, all-pervading management regimen are indicated.

Because the parents interviewed for this study all formed part of a two-parent family, interaction patterns, support roles, management of care for the young child, and stress, conflict, and parents’ needs were all explored from the perspective of the integrated experience of two parents. Consequently, the
unique needs of a single parent were not considered. This study indicated the inordinate amount of stress experienced for both parents when an infant or toddler is diagnosed with diabetes. It also revealed the necessity for teamwork and sharing the responsibility of care between two parents. The families in this study indicated how imperative it was that both parents be involved in procedures such as insulin injections. Many parents described their responsibility and involvement as never-ending, and indicated that they couldn’t imagine how a single parent could manage the complex regimen alone. This indicates that further studies to examine the stressors, responses and coping behaviours of a single parent caring for an infant or toddler with diabetes are required. Based on the findings of this study, exploration and understanding of the support required for single parents is recommended.

Data from this study also indicated a lag in developmental milestones for some toddlers who were diagnosed after the age of two years. This finding was associated with the physiological ramifications of diabetes, and the overprotective behaviours of parents. Conversely, parents of infants diagnosed very early in life reported their young children as being advanced both cognitively and physically, and demonstrating assertiveness or even aggressive behaviour. No previous studies were found to refute or to support these findings. Consequently, studies into the development of such young children with a chronic long-term illness, compared to the age at diagnosis, are indicated and recommended by this researcher. Further studies into the problems faced by parents because of the young age of the child, and the child’s inability to communicate and cooperate with the required management regimen, are also indicated. Exaggerated behaviour on the part of infants and toddlers concerning other procedures, such as removing slivers or applying cream to infected areas, were also described by parents who had difficulty understanding these concepts. Association between invasive, painful management procedures and an infant’s or toddler’s fear and exaggerated behaviour should be further researched.

Parents in this current study also identified anticipatory worries about future events in their child’s lives, such as entering pre-school or kindergarten, or being alone without the ability to recognize or
communicate their own feelings or needs. This anticipatory worry on the part of parents indicates that longitudinal studies of this cohort group and other parents who have infants or toddlers diagnosed with diabetes should be conducted. Understanding how the parent and the child cope and adapt over the long term would provide useful information for health care providers who are also involved in the care and management of these families as they progress through these developmental phases of their lives.

In the current study, parents also identified the impact their young child’s diabetes had on their decisions to have other children. Possibly a limitation or unique feature of the participants in this study was that, in most families, the child with diabetes was the first child. Although one of the families had an older child, and three families had younger infants born during the course of the study, the major impact of a young child’s diabetes on siblings was only briefly addressed.

Many of the fears, stressors, struggles, frustrations, responses and strategies employed to cope with the needs of a young diabetic child could also be generalized to the experiences of parents caring for young children with other chronic conditions. For example, the sustained or underlying fear of hypoglycemia for the parents in this study could also be compared with the fear of seizures in an epileptic child, or an asthma attack in a child with severe allergies, or a blocked airway for a child with a tracheostomy. The parents reported loss of flexibility, spontaneity, freedom and support systems, and their lack of trust in others to care for the child, could be equally experienced by parents of other young children with chronic conditions. Consequently, further qualitative studies to examine the experiences of parents caring for infants and toddlers with other chronic conditions is indicated.

Although many studies have been conducted to examine the parents’ reactions to an acutely ill child’s hospitalization, and many studies examine the parents’ perceptions of intermittent hospitalization of the chronically-ill child during the trajectory of a disease over the long term, few have been found that examine the problems associated with the acute and sudden onset of a condition such as diabetes in an infant or toddler. Because the acute phase is immediately followed by the parents’ need to adapt to a
chronic lifelong condition in their child, more studies to promote understanding of the parents’ need during this initial hospitalization experience are recommended. Data collected would be of inordinate benefit to health care professionals who are assessing, planning care and education, and implementing interventions for the child and family, both initially and over the long-term.

There is a paucity of research available that addresses the parents’ perceptions of their experiences of caring for an infant or toddler with diabetes. The qualitative method of research promotes in-depth understanding of the parents’ perspective of their situation. Therefore, more studies conducted using this method are recommended.

Implications for Nursing and Technological Research

One conclusion reached from findings of this study had implications for both nursing and technological research. Parents in this study relied implicitly on blood sugar monitoring to determine their infant’s or toddler’s metabolic control, and insulin and dietary needs. Because these young children were unable to communicate their own feelings, parents also relied on blood sugar readings for anticipating or determining episodes of hypoglycemia or hyperglycemia. The blood testing became a lifeline to parents and a way of knowing when to call health care professionals for advice. Parents admitted to being totally vigilant with this procedure. They tested the child’s blood regularly four times daily, and often during the night or during daytime naps. They described this as being “the way to know what’s going on inside my child.” Blood tests were done in shopping malls or on beaches. Parents had great difficulty trusting their child to anyone who could not perform and interpret blood tests. This had implications for available support systems.

Despite bruised fingers, the toddlers and infants were described as being very accepting of the blood testing procedure. They often assisted with tests, or at night, slept through them. Because of this, parents tended to become overvigilant and totally reliant or almost obsessed about blood testing.
Because health care professionals also rely implicitly on blood sugar results for managing the young child with diabetes, they tend to encourage and promote this vigilance in parents. However, overanxious and obsessive behaviour on the part of parents should be recognized, and mutually acceptable ways of handling blood tests and reducing the parents' anxiety should be worked out. Nurses should devise finger rotation patterns that reduce the probability of bruising and infection. In very small infants, alternative sites could be suggested.

The implications for developing a reliable, non-invasive blood monitoring device are increased due to the needs of this growing population of infants and toddlers with diabetes. Although such a device would also benefit older children and adults, it would be a major breakthrough in management for young children who require such constant monitoring. Although research in this field is progressing, parents often receive inaccurate or false information on the availability of such devices. Providing accurate and honest information about the availability and reliability of such devices should be the responsibility of not only the researchers, but nurses and other health care professionals who support, teach and care for these families.

In conclusion, the parents' experience of caring for an infant or toddler with diabetes has not yet received the attention it deserves in health care planning, intervention or research. Because the incidence rate of insulin-dependent diabetes mellitus in children under the age of three years is increasing, the unique management problems and special needs of this emerging subgroup of chronically-ill children and their parents should be addressed. Only by listening to the parents' accounts can nurses and other health care professionals grasp the full meaning of this experience from the parents' perspective.
References


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APPENDIX A

Participant Information Letter and Consent Form
Parents’ Perceptions of Caring for Infant Diabetes

Dear Parents or Caregivers,

My name is Doreen Hatton. I am presently doing graduate work in the Master of Science in Nursing Program at the University of British Columbia. For my Master’s Thesis I am studying the experiences of parents who are caring for a young child (toddler or infant) with diabetes mellitus. Over the past five years I have worked as a Nurse Clinician/Nurse Educator on the Diabetic Management Team at B.C.’s Children’s Hospital, and have become acutely sensitive to the needs and concerns of children with diabetes and their families. Because of the increasing population of young children under three years with diabetes it is important that the perceptions of parents, who care for this unique group of young diabetics, are better understood. It is already recognized that bringing up a young child is a challenge without the added concerns of dealing with diabetes. Consequently, this study will contribute to our knowledge and understanding of the parents’ or caregivers’ own perceptions of their experiences about caring for a young child with diabetes on a day-to-day basis, and will help nurses and other health care professionals to be more responsive to the needs and concerns of families such as yours. We recognize that young children with diabetes present a major challenge to health care professionals as well as to parents, and your ideas about how diabetes impacts on yourself, your child, and your family could help us to form closer working relationships with all family members.

If you are interested and agree to participate in this study, I will arrange to meet with you for interviews, either in your home or in a comfortable environment selected by yourself. I anticipate there will be two or three interviews, each lasting approximately one hour, and I will invite you to share your experiences of what it is like to live on a day-to-day basis with a young child who has diabetes. The interviews will be tape-recorded, but no identifying information will be used in the study. Anonymity and confidentiality of information will be maintained. The tape-recorded data will only be shared with members of my thesis committee, and the tapes will be erased immediately following completion of the study. No names or identification will appear in any written reports or in the final thesis document. I wish to assure you that you are under no obligation to participate in this study, and that if you do agree to participate, you have the right to withdraw from the study at any time. Non-participation or withdrawal from the study will in no way jeopardize your child’s care or alter your relationship with the Diabetes Management Team at B.C.’s Children’s Hospital. If you agree to participate, you may terminate an interview or request erasing of a tape at any time. My reasons for tape recording interviews are that it will enable me to concentrate on ideas, concerns and issues expressed by yourself, and later compare these ideas with the ideas of other parents participating in the study.
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The potential benefits and outcomes of this study will be my increased knowledge and understanding of your experiences, which I can then share with others involved with working with families who are also caring for young children with diabetes.

If you are interested and willing to participate in this study, please could you contact Ann McKenzie, the clinic nurse of the Diabetes Program at Children’s Hospital, and leave your name and telephone number with her. A message could also be left with the Diabetes Program Secretary if the clinic nurse is not available. I will then contact you and explain the purpose of the study more fully.

If you have any questions about the study or would like more information, please feel free to contact me through the Diabetic Clinic at Children’s Hospital (875-2868). A message can be left for me with the clinic nurse and I will return your call immediately. Professor Connie Canam and Professor Sally Thorne, members of my thesis committee, would also be available to answer any questions you may have. Telephone numbers are provided for your convenience at the end of this letter, or a message could be left on my answering machine.

Thank you most sincerely for considering this request.

Doreen L. Hatton

If you are willing to participate in the study, a Participation Consent form and letter will be provided for you.

Telephone numbers to provide information or to answer your questions:

Diabetic Clinic, B.C. Children’s Hospital 875-2868
Doreen Hatton, answering machine 736-3928

Thesis committee:

Connie Canam, M.S.N., R.N. (Chair), Assistant Professor 228-7558
Sally E. Thorne, Ph.D., R.N., Associate Professor 228-7482
Participation Consent Form

Title of Study: Parents’ perceptions of their experiences about caring for their young child under three years who has insulin-dependent diabetes mellitus.

Investigator: Doreen Hatton, B.S.N., R.N. 736-3928
Thesis Committee: Connie Canam, M.S.N., R.N. (Chair) 228-7558
Assistant Professor
Sally E. Thorne, Ph.D., R.N. 228-7482
Associate Professor

The purpose of this study is to explore and describe the lived experiences of parents who are caring for a young child under three years with diabetes, and to gain insight and understanding into this experience from the parents’ perspective. This study will involve two or three interviews of approximately one hour. Interviews will take place in your home or in a comfortable environment selected by yourself. The interviews will be tape-recorded but no identifying information will be used in the study. The tape-recorded data will only be shared by members of the thesis committee, and the tapes will be erased immediately following completion of the study. No names or identification will appear in any written reports or in the final thesis document, and anonymity and confidentiality of information will be maintained.

You are under no obligation to participate in this study, and should you agree to participate, you have the right to withdraw from the study at any time. Non-participation or withdrawal from the study will in no way jeopardize your child’s care or alter your relationship with the Diabetes Management Team at B.C.’s Children’s Hospital.

Should you agree to participate, you have the right to refuse to answer any questions or to stop an interview at any time. You may also request erasure of any tape, or portion of a tape, at any time during the study.

The overall results of this study may be published or presented at conferences to provide nurses and other health care professionals with knowledge and understanding of parents’ perceived experiences of caring for a young child with diabetes, and to help nurses become more responsive to the needs of families such as yours.

If you consent to participate in this study as described, please sign below in the space provided.
If you have further questions about the study, please ask the investigator prior to signing this consent form.

I/We understand the nature of this study, and give my/our consent to participate. I/We acknowledge receipt of a copy of the participants’ information letter and consent form.

Signatures:

Date:
APPENDIX B

Sample Questions for Initial Interview
Sample questions for initial interview

General questions will be asked to elicit the parents' perceived experiences. More specific probe questions will be used only in the event that the investigator requires clarification, or that a particular aspect of the experience was not sufficiently described or discussed by the parents.

1. What is it like for you as a parent to have a young child under three years with insulin-dependent diabetes?

2. How would you describe your experiences of caring for a young child [will use child’s name(*)] with diabetes?

3. How does the daily diabetic regimen affect your child (*), yourself and your family?

(Example probe questions, if necessary):

- What do you think it is like for your child to have diabetes?
- Can you describe how you cope with your child’s needs?
- What is it like for you to give insulin injections?
- What do you think it is like for your child?
- What are your thoughts at the time?
- What is it like for you to monitor your child’s blood sugar several times a day?
- What do you think it is like for your child?
- How do you feel about these procedures?
- What are your thoughts if your child struggles and cries?
- What effect does this have on your other child(ren), or other members of the family?

4. I’d like to understand more about how you manage your child’s (*) diabetic control.

- How do you perceive "good" or "bad" diabetic control?
- Can you describe how you manage your child’s diabetic diet?
- How do you feel and react when your child will not eat?
- How do you cope with low blood sugars?
- What do you do if your child complains about still being hungry when the prescribed amount of food has already been eaten?
- How do you feel and react when your child overeats?
- Can you share your thoughts about high blood sugars?
- How do you care for your child during illnesses and infections?
- Are there people you rely on to help you through these experiences?
5. What are the major changes you have experienced in your family life since your child (*) was diagnosed with diabetes?

6. What is it like for you to share your experiences?
   - What do you think this could mean to you?
APPENDIX C

Framework Of Themes From Parents Accounts
Parents’ Perceptions of Caring for Infant Diabetes

Phase One: The Diagnosis of Diabetes

Perceived Stressors
- Receiving the diagnosis
- The hospital experience
- Learning the diabetic management regimen
- Build up of stressors

Reactions and Emotional Responses to Perceived Stressors
- Functioning like robots
- Denial
- Feeling trapped
- Blaming
- Guilt and anger

Coping Strategies Employed by Parents to Manage the Situation
- Being assertive
- Learning to manage the young child’s condition
- Seeking support
- Understanding and describing the child’s condition
- Looking for a cause
- Considering alternatives
- Clinging to hope

Phase Two: Caring for the Young Child at Home

Perceived Stressors
- Taking the infant or toddler home
- Changes in lifestyle
- Perceived losses
- Unpredictable blood sugar levels
- Hyperglycemia and hypoglycemia
- Confrontations over food
- Giving injections
- Taking blood tests
- Child’s development

Reactions and Emotional Responses to Perceived Stressors
- Emotional responses
- Changing roles, relationships, conflicts and friction
Coping Strategies Employed by Parents to Manage the Situation

- Being methodical and vigilant
- Making decisions
- Sharing responsibility
- Interacting with health care professionals
- Trusting others
- Identifying needs: reducing stress
- Maintaining hope

Phase Three: Adapting over the Long Term

Perceived Stressors

- Issues related to insulin injection
- Conflicts over diabetic control
- Issues related to food
- Behavioural issues
- Anticipatory worry
- Decisions to have other children

Reactions and Emotional Responses to Perceived Stressors

- Recurring and sustained emotional responses

Coping Strategies Employed by Parents to Manage the Situation

- Taking charge
- Being flexible
- Maintaining vigilance
- Trusting others
- Building supports
- Growing as a family
- Managing stress and worry
- Sharing, talking (hidden benefit of study)
- Comparing with alternatives
- Accepting the realities of diabetes