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Juvenile diabetes: A study of children’s perceptions of their illness

Zahorik, Pamela Marie, Ph.D.
Case Western Reserve University, 1991

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JUVENILE DIABETES: A STUDY OF CHILDREN'S
PERCEPTIONS OF THEIR ILLNESS

by

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Submitted in partial fulfillment of the requirements
for the Degree of Doctor of Philosophy

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Pamela Marcia Lukowik
JUVENILE DIABETES: A STUDY OF CHILDREN'S
PERCEPTIONS OF THEIR ILLNESS

Abstract

by

PAMELA MARIE ZAHORIK

Children with chronic illnesses have a unique set of health and illness experiences. The purpose of this research was to investigate how children with juvenile diabetes (IDDM) explain, manage and cope with their illness. Three sets of interviews were administered to twenty-six children who were diagnosed as diabetic for at least six months. Theoretical perspectives were gathered in initial and follow-up interviews. Weekly interviews, gathered by telephone, investigated health maintenance activities and actual response patterns to illness episodes.

Results indicate that although juvenile diabetes is a fully recognized entity in the realm of professional biomedicine, it is the popular sector of care which has the greater influence on diabetic illness beliefs, management behaviors, and coping strategies. The
children's responses also indicate that they view their condition from two perspectives. The first is a disease orientation in which juvenile diabetes is seen as a complex, life-threatening, medical condition which is caused by a malfunctioning pancreas. This disease orientation is mediated by an illness orientation, which has management as the focal point. The diabetic management tasks of insulin injections, blood or urine checks and vigilance in diet and exercise are clearly delineated in the professional sector of care, but are carried out in the popular sector of care.

By successfully participating in self-care, these children learn that they can become responsible for their health. Since several of the prescribed diabetic management tasks are recommended for all health-conscious individuals, the paradigm of care for these children becomes one of health maintenance as opposed to diabetic illness prevention.
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TABLE OF CONTENTS

LIST OF FIGURES ......................................................... viii
LIST OF TABLES ........................................................... ix
LIST OF APPENDICES .................................................... x

CHAPTER                                      PAGE
I    OVERVIEW ......................................................... 1
II   LITERATURE REVIEW ............................................. 5
III  METHODOLOGY ..................................................... 55

IV   RESULTS
     Knowledge about Juvenile Diabetes ................. 73
     Management ..................................................... 93
     Limitations and Coping .................................... 119

V    CONCLUSIONS .................................................... 139

APPENDICES ............................................................. 151
LITERATURE CITED ................................................... 161
### LIST OF FIGURES

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Simultaneous Plot of Symptoms and Responses</td>
<td>109</td>
</tr>
<tr>
<td>II. Two-Dimensional Representation of Perceived Limitations of Diabetes</td>
<td>124</td>
</tr>
</tbody>
</table>
# List of Tables

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. &quot;What causes diabetes?&quot;</td>
<td>79</td>
</tr>
<tr>
<td>2. &quot;How does insulin work?&quot;</td>
<td>89</td>
</tr>
<tr>
<td>3. Type of Test Conducted to Determine Glucose Levels</td>
<td>98</td>
</tr>
<tr>
<td>4. Who Administers Insulin Injections and Conducts Tests?</td>
<td>103</td>
</tr>
<tr>
<td>5. Health Management Strategies</td>
<td>116</td>
</tr>
<tr>
<td>6. &quot;Is there anything you don't like about diabetes?&quot;</td>
<td>122</td>
</tr>
<tr>
<td>7. Generated Lists of Stresses</td>
<td>130</td>
</tr>
</tbody>
</table>
# LIST OF APPENDICES

<table>
<thead>
<tr>
<th>APPENDIX</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Initial Interview</td>
<td>151</td>
</tr>
<tr>
<td>Weekly Interview</td>
<td>154</td>
</tr>
<tr>
<td>Follow-Up Interview</td>
<td>156</td>
</tr>
<tr>
<td>II. Multi-dimensional Scaling - Figure I</td>
<td>159</td>
</tr>
</tbody>
</table>
CHAPTER 1

OVERVIEW

"Maybe someone else will hear what I know. I know a lot about diabetes."

----- 13 year old diabetic child

The purpose of this research was to gain an understanding of how children with the chronic illness, juvenile diabetes, explain and manage their condition. A second goal was to explore these children's participation in illness resolution and health maintenance strategies. A third goal was to determine if children are meaningful informants on health and illness issues, and to lend support to the benefits of eliciting their beliefs and analyzing their behaviors.

Illness is a biological, social and cultural phenomenon. Enculturation into the cultural aspects of illness begins at birth and we can learn more about this vital system and its participants by noting the processes through which neophytes are taught the shared beliefs, values and behaviors of their culture. Studying the thoughts and actions of children lends clues to the beliefs and behaviors of the adults they will become.

Insufficient attention has been focused on children's perceptions of health and illness states in
themselves. The reason for this neglect is two-fold. Children are viewed as "immature members of their societies, with limited access to resources and limited knowledge and experience" (Korbin and Zahorik 1985). This is coupled with the reality that children do not and cannot act independently in the health care system. Parents must act as mediators in obtaining medical care and provide release for the child from other responsibilities. The result is a disregard of children as meaningful cultural informants, and a neglect of investigation into the forces that move a child toward maturity with its attendant concepts and behaviors.

The study of children's health and illness experiences and perceptions not only provides valuable information about the acquisition of knowledge and the development of adult patterns, but also provides practical information to be applied to the clinical arena, in particular, the areas of doctor/patient relationships and adherence to prescribed medical treatments. This, coupled with recent research indicating that by the time children reach school age, health-related orientations are surprisingly stable (Bush and Iannotti 1988), should stimulate increased investigation of these subjects, with recognition of the value of children as informants.
Children with diabetes are a population well suited to research on the development of health and illness attitudes. Juvenile diabetes is a chronic, life-long illness, for which strict daily management is the only form of treatment. Children with diabetes are faced with a condition that produces short-term imbalance episodes and has life-long health and illness implications. Thus, diabetic children are developing sets of beliefs and behaviors that will carry them into adulthood.

In addition to this, there is an interest in the impact of chronic illness on the life world of children (Bluebond-Langner 1978; Kleinman 1988). The parameters of illness experiences go beyond the clinical setting to impact the psychological, social and cultural selves. The experience of having juvenile diabetes cannot be separated from the progression through daily life, they must be integrated. As a result of this synthesis, both the effects of daily living on illness, and the impact of having an chronic illness on daily life, intensify one another and create a unique life world.

This dissertation is organized into five chapters. Chapter 2 contains pertinent literature from the fields of chronic illness, diabetes mellitus and medical anthropology. Anthropology has contributed theory, perspective and methodology to this research. An understanding of the individual's perspective on issues
of health and illness leads to greater satisfaction for all involved in the variety of medical systems. Unfortunately, the perspectives of ill children rarely have been gathered. This research demonstrates the benefits of focusing on this segment of the population.

Chapter 3 outlines the three sets of interviews used to gather data with diabetic children. Theoretical perspectives were gathered in an initial and a follow-up interview. Actual response patterns to illness episodes, and actions taken to ensure good health, were explored in weekly interviews.

Chapter 4 presents analyses of results. Three general areas of inquiry are included in the results section: the children's knowledge about diabetes; their perceptions about, and participation in diabetic management procedures; and their insights and attitudes while dealing with perceived stress and limitations as they strive for normality. Conclusions, and future research directions, are summarized in Chapter 5.
CHAPTER II

LITERATURE REVIEW

The study of children's experiences of diabetes requires consideration of three bodies of literature. First, the chronic illness literature illustrates aspects which are common to the experience of all types of chronic illnesses, in particular those illnesses which require care outside the medical sphere. Second, the literature on diabetes gives insight to the past focus on the biomedical aspects of the condition, and further clarifies how the management component of the illness makes an impacts on the children and their families. Third, the medical anthropology literature provides a framework within which the investigation and analysis of diabetic children's beliefs, management behaviors and coping strategies may be conducted.

CHRONIC ILLNESS

Medical technology is contributing to the growth of the chronically ill segment of the population. Improvements in medicine have resulted in a reduction of infectious disease which, coupled with life-prolonging
efforts, has made survival possible for individuals who previously would have died from disease, birth trauma or injury. The elderly live longer and, with the additional years, develop chronic conditions. At the opposite end of the life cycle, children live in a technological age which offers management, but no cures, for most chronic illnesses.

There are more than one million children with severe chronic illness in the United States, and an additional 10 million living with less severe chronic illnesses (Haggerty 1984). Although the incidence rate of specific chronic illnesses have not risen in recent years, an increased survival rate has raised dramatically the prevalence of chronic illnesses (Perrin 1985; Gortmaker and Sappenfield 1984; Pless and Roughmann 1971). Although differing prevalence rates exist for specific illnesses and populations, it is estimated that a range of 10–20 percent of all children will suffer a chronic disorder (Perrin 1985; Gortmaker and Sappenfield 1984; Pless and Roughmann 1971).

Children with chronic illness are an increasing concern for pediatricians; current figures indicate a rise from 4 percent of pediatric visits for chronic problems in the 1960’s, to 13 percent of pediatric visits in the 1980s (Gortmaker and Sappenfield 1984). Diagnosis and management of chronic conditions may span long
periods encompassing several important growth intervals in a child's life. Children with chronic illness also utilize an increasing percentage of hospital services (Gortmaker and Sappenfield 1984), and participate in a wider range of medical and social services.

Chronic illness appears in many forms. It may be characterized by obvious physical deformity or may not be outwardly apparent. It is interesting to note that the majority of literature concerning chronic illness does not provide a concise definition of the chronic state. A general definition of chronic, as distinguished from acute, is "lasting a long time and recurring" (Webster's New World Dictionary 1962). Viney and Westbrook (1981) define chronic illness as a medical condition which would last at least six months and/or cause permanent disability. This time frame was altered to three months by McCollum (1981). These definitions do not consider the social concomitants of chronic illness, focusing instead on the medical aspects. Ferrin (1985) improves this definition slightly by stating:
Chronic illness is a condition that interferes with daily functioning for more than three months in a year, causes hospitalization of more than one month in a year, or (at time of diagnosis) is likely to do either of these.

Perrin's definition is more complete, since it considers the effect of an illness on daily functioning. However, requiring a hospital stay disregards the constant attention to care given outside the hospital system. Individuals might experience chronic conditions and not enter the hospital in the span of a year.

Defining chronic illness by either permanency of disease and irreversability of pathologic process, or a residual disability and need for extended care and observation (Lipp 1977), excludes the fact that a medical condition may exist for only a set amount of time but the social consequences may be irreversible. Further confusion arises with the term "handicapped," which has an evolving use which excludes internal or "invisible" conditions, but is often used in place of the term "chronic."

The working definition of chronic illness utilized in this research is:

a constant or recurring condition, having medical and social implications, which may require hospitalization but does not necessitate management outside an acute care facility, and which includes physical impairments or invisible internal conditions, or both.
This definition is preferred because it includes:

(1) consideration of the medical and social aspect of chronicity;
(2) recognition that the majority of care may occur outside the sphere of professional medicine and
(3) identification of chronic conditions with obvious physical manifestations as well as conditions that may only become apparent through the necessary behaviors associated with them.

This expanded definition defines many chronic illnesses but, in particular, demarcates conditions such as diabetes, cystic fibrosis, sickle cell anemia, asthma and other illnesses. These illnesses, which at times are not immediately discernable, necessitate management in the home and have substantial social as well as medical consequences.

Severity of chronic illness can be measured in several ways. One guideline measures severity according to:

(1) a large financial burden of 10 percent of family income after taxes
(2) the degree to which illness restricts physical development
(3) the degree to which the illness impairs the ability of the child to engage in accustomed and expected activities
(4) the degree to which illness contributes to emotional or psychological problems for the child
(5) the degree the illness contributes to disruption in family life as indicated by marital function or sibling behavioral disorders (Perrin 1985)
DIABETES MELLITUS

Diabetes mellitus is a condition that encompasses the definition of a chronic illness in every way. Simply stated, diabetes is a metabolic disorder that results from the insufficient production of, or the complete lack of the hormone insulin. Diabetes is a serious, life-long condition affecting every organ system of the body and requiring careful daily management (Guthrie & Guthrie 1983).

Diabetes mellitus is an ancient syndrome which was first recorded in Greece and India some 1500 years before Christ (Guthrie & Guthrie 1983; Krail 1978). The term "diabetes" comes from an Ionic Greek word meaning "to run through a siphon." This was later combined with the word "mellitus," a Latin word for "honey," referring to the high sugar content in the urine of affected individuals. A 17th century English medical journal described the condition as "the pissing evile [sic]" noting the fact that an uncontrolled diabetic condition produces an excess amount of urine (Bliss 1982). Clinical manifestations were described as the triad: polyphagia (excessive eating); polydipsia (excessive drinking); and polyuria (excessive urination) by the ancient Chinese. The use of this triad continues today.
As early as the 6th century, two types of diabetes were differentiated: a maturity onset distinguished by patients being "obese and without energy," and an onset in youth described as "melting down of the flesh and producing sweet urine" (Krall 1978).

In the 19th century, two discoveries made in Germany advanced the understanding of diabetes. First, Joseph von Mering and Oskar Minkowski found that if they removed the pancreas from animals, diabetes developed (Aloia et al. 1984). Second, Paul Langerhans described specific clusters of cells in the pancreas, the islets of Langerhans, which were later discovered to contain the cells that release insulin. An American, E.I. Opie, advanced the work of the Germans when he found that it was specifically these islet cells that were damaged in diabetic individuals. Insulin, the hormone responsible for blood glucose regulation, was discovered in 1921 by Fredrick Banting and Charles Best. The possibility of living to maturity with juvenile diabetes was not a reality until that time.

Ten to twelve million Americans develop some form of diabetes. This translates into an estimate that 5% of Americans have diabetes and this rate is on the rise (Krall 1978). Diabetes is the third leading cause of death by disease in the United States (Guthrie & Guthrie 1983), and is a contributing factor to other causes of
death such as heart disease, kidney disease, and stroke. Diabetes is the most common of the serious metabolic diseases of humans (Foster 1983) and is the most common endocrinopathy in childhood (Rosenbloom 1984).

Classification

There are two distinct forms of diabetes mellitus, which were renamed by the National Diabetes Data Group in 1979. These classifications are Type I, insulin-dependent diabetes mellitus (IDDM) and Type II, non-insulin dependent diabetes mellitus (NIDDM).

Non-insulin dependent diabetes most often occurs later in the life cycle, and is linked with obesity. Individuals with this form of diabetes may produce insulin, but not in sufficient amounts for glucose metabolism. Preferred theories of malfunction include insulin levels that are normal but are insufficient for increased body weight. A second theory points to fewer functioning "receptor areas" on the peripheral cell membranes (Guthrie and Guthrie 1983; Krall 1978), so insulin may not be utilized efficiently, thus exacerbating the problem. Type II diabetes often can be controlled by diet and weight loss, and usually does not require daily insulin injections as part of the management procedures. This is the more
prevalent form of diabetes, occurring in as many as 85% of all diagnosed diabetic cases.

Type I (IDDM) most often manifests itself in youth, with peak incidences occurring at 5 and 11 years of age, but onset can occur at any age. The term insulin-dependent is descriptive of the necessity of daily insulin injections.

The children in this study were diagnosed as having Type I diabetes (IDDM). Although recognition is given to the preferred nomenclature of the National Diabetes Data Group, the term juvenile diabetes is utilized in this text since:

1) research was conducted with children between the ages of seven and twelve who were all insulin-dependent; thus the term juvenile diabetes is descriptive of the target population
2) the term "juvenile diabetes" is frequently used in the literature on diabetes, and is a well recognized term in both medical and non-medical spheres

Etiology

The etiology of diabetes is unknown. There is speculation that the propensity to develop the condition is inherited rather than acquired. It is hypothesized that some trigger, perhaps a viral infection, causes an immunological response which damages the insulin-producing beta cells in the pancreas (Cahill and McDevitt 1981; Keen 1984). The viral trigger hypothesis is
supported by the seasonal variation in diagnosis, with peaks in spring and late fall, and a similar pattern in the Southern Hemisphere, but in opposing six month intervals (Cahill and McDevitt 1981; Foster 1983; Drash and Berlin 1985).

It also has been noted that a diagnosis of diabetes often follows episodes of viral infections, such as hepatitis, mumps, Coxsackie virus and infectious mononucleosis (Foster 1983; Krall 1978). When blood studies are conducted soon after the onset of diabetes, antibodies affecting the beta cells have been found in the blood stream of diabetic individuals.

Genetic factors influence the incidence of diabetes mellitus, although in varying degrees. Monozygotic twin studies yield a less than 50% concordance between a diabetic individual and his or her twin when the individuals studied are under forty years of age. Twins over forty years of age, who have non-insulin dependent diabetes mellitus, show close to 100% concordance (Foster 1983). This seems to suggest a stronger genetic influence in the non-insulin dependent form of the disease.
Disease Process of Juvenile Diabetes

The pancreas contains beta cells which are located in the islets of Langerhans. These cells secrete insulin, which reduces the glucose level in blood. If insulin is present, metabolized food is able to enter the cells and is used for energy production. The pancreas also contains glucagon-secreting alpha cells which increase the glucose level in blood. In simple terms, insulin reduces sugar levels in blood, and glucagon raises these levels. Alpha and beta cells in the pancreas are activated in response to raised glucose levels. This regulation of glucose is in precise proportion to the food ingested and the metabolic needs of the body. A functioning pancreas is capable of measuring blood glucose levels every ten seconds, within a reliable range of 2 mg. percent (Krall 1978).

In a diabetic individual, insulin-producing cells are damaged, and glucose cannot be metabolized and utilized by the cells. Thus, an individual without insulin feels tired and weak. The cells are not receiving vital nutrients, so a permanent feeling of hunger may exist, and overeating (polyphagia) occurs. The body reacts as if in a state of starvation, and begins to break down stored fuels (glycogen, fats and muscle tissues) in an effort to produce these nutrients.
None of these sources of fuels can be utilized, due to the lack of insulin, and are circulated through the kidneys and out of the body. Polyuria (excessive urination) begins as the body tries to eliminate an excess of glucose. This fluid loss leads to tremendous thirst, which serves to perpetuate the cycle of persistent hunger and thirst without viable means of satisfying cellular needs.

Glucose also can act as a toxic substance, and in excess can promote damage to blood vessels and nerves (Guthrie & Guthrie 1983). This is why diabetics may suffer from complications such as retinopathy and neuropathy, as well as heart and kidney disease. In the United States, 50% of amputations of the foot and leg in adults, 20% of kidney failures, and 15% of blindness are due to complications of diabetes (Ducat 1983).

Before the discovery of insulin, children with diabetes wasted away while experiencing acute hunger. The treatment of the day was to reduce drastically the intake of food, since this prevented the development of ketoacidosis, which if left untreated could lead to coma. The result in either case was starvation. Injected insulin allows the utilization of glucose as a nutrient for the cells. Injected insulin cannot yet replicate the perfect amount and release of an active pancreas; but
with careful monitoring and balancing of diet and exercise, injections do allow for an extended life-span.

Management of Juvenile Diabetes

In the treatment of diabetes, the closest thing to a cure is constant management vigilance. Health and illness in diabetic individuals depends on several factors, the most important being the daily balance of insulin, food, and exercise. Management of these factors is a delicate operation and varies with each individual. Diabetic children are no longer faced with imminent death, but must develop regulation strategies for long term and daily management of their condition. Stress, emotional factors and illness all must be taken into consideration since the body’s glucose levels may change in reaction to any of these factors. Failure to successfully manage the diabetic condition may lead to episodes of ketosis and hypoglycemia in the short run and the previously mentioned chronic hazards of retinopathy, neuropathy, kidney and heart disease in the long run.

Although it has been stated that there is a lack of conclusive proof that good control will prevent complications (Lowrey 1962; Ziporyn 1984), there is currently no alternative strategy to good management. Although not a guarantee of perfect health, improved
blood sugar levels may postpone or minimize future complications (Krall 1978; Keen 1984). Tight management also impacts on short-term health. Episodes of imbalance (hyperglycemia or hypoglycemia) can have immediate impact on physical and mental functioning. Therefore, the incentive to maintain diabetic balance is to allow for daily functioning and to avoid future complications.

As with many chronic illnesses, adherence to medical advice is a major concern. It has been suggested that 25% to 50% of all patients act at variance with physician suggestions (Trostle et al. 1983). Diabetes places the majority of responsibility for management on the child and the family. Daily tasks of insulin injection, blood or urine tests, diet, and exercise must be coordinated in the home. This often requires major changes in the lifestyle of the child and the rest of the family. An understanding must be reached between the child, family and medical professional for optimal management to be attained.

Various findings have been reported on those aspects of diabetic management that are shown to be as most stressful. In a study with 30 diabetic children interviewed in 1966 and again in 1975, insulin injections were reported as most "bothersome" (Galatzer, Frish, and Laron 1977). Similar feelings about injections also were
reported by Frish et al. (1977) and for elementary school aged children by Kosub and Kosub (1982).

Psychosocial Development

The majority of literature concerned with juvenile onset diabetes is biological in nature and focuses on the clinical manifestations of diabetes and the necessary management procedures involved with the condition (Brown and Thompson 1940; Danowski 1979; Krall 1978; Podolsky 1980). The discovery of insulin in 1921 allowed for increased life expectancy and recategorized juvenile diabetes from a fatal to a chronic illness. The immediate concern of research was to develop management strategies to bring the diabetic condition under control and prolong life. Medical breakthroughs have improved biological health in these children, but further information is needed to understand the social and cultural implications of the diabetic condition.

Psychosocial problems seem to occur two to three times more frequently in chronically ill children than in healthy peers (Weitzman 1984). This may be due to the fact that chronic illness presents the child with special problems. Stigmatization due to appearance, a misunderstanding of contagion, physical limitations which exclude participation in some activities, and
differentiating activities such as the need to take medications or eat at specific times all enforce an attitude of separation. Each stage of the socialization process presents new tasks and opportunities. Thus, continuing adjustment and acceptance evolve concerning the illness. Even if the illness does not last a lifetime, there is evidence that socialization may be an area of vulnerability for those who have survived a chronic illness (Gogan et al. 1979; Korsch et al. 1973; O’Malley et al. 1979).

Isolation may increase because of frequent school absenteeism due to illness or hospitalization. Students believed by teachers to be less accepted by peers have greater numbers of health visits (Van Arsdell et al. 1972). This adds to self-perpetuation of a destructive spiral. This is reflected in research findings indicating that, although the majority of chronically ill children attain the same intelligence level as their healthy peers, the ill children seem to be underachievers and do worse academically (Weitzman 1984). Data from Pless and Roghmann (1971) further support the observation that chronically ill children are at risk for poor academic achievement.

The Isle of Wight study, from which Pless and Roghmann drew some of their data, was designed primarily to determine the educational consequences of physical and
emotional handicaps (Pless and Rohmann 1971). It was discovered that there was a significantly higher proportion of chronically ill children who were retarded, by 28 months or more, below their expected level of reading achievement, after age and I.Q. had been taken into account (Rutter et al. 1970). Data from the National Survey, also used by Pless and Rohmann, showed that aggregate scores on tests of achievement also are significantly below those of healthy children (Douglas 1964); "the greater the severity of the condition, the greater the extent of underachievement" (Pless and Rohmann 1971:355).

Psychological factors can affect the management and control of diabetes. Emotional problems of diabetic children have been studied using kinetic family drawings depicting feelings of isolation and food deprivation (Sayed and Leaverton 1974). Simonds's (1977) study revealed a greater number of interpersonal conflict among children with poor diabetic control. Koski (1969) found that poor control of blood sugar levels could produce feelings of guilt in children. Emotional problems arose from the constant necessity for management, plus the stigma of being diabetic.

Tietz and Vidmar (1972) viewed psychosocial factors through the degree of metabolic control. In their study of 21 children from a pediatric diabetic clinic, they
found no correlation between degree of metabolic control and age of onset, duration of illness, number of siblings, interactiveness of family, degree of family psychopathology, intelligence of child and parents, birth rank, ethnicity, social class, or knowledge about diabetes. The factor they found that correlated positively with degree of control was the family history of diabetes. Non-correlation of the level of knowledge about diabetes with the degree of metabolic control was echoed in a study of individuals aged 16-81 (average age 55 years) by Watkins et al. (1967). They reported that individuals with the highest levels of cognitive understanding of the disease had the poorest level of metabolic control.

One dimension of personality that psychologists have used to investigate children's concepts of illness is the internal/external locus of control construct. Those diabetic children who exhibit an internal locus of control, which is the belief that one has control over their environment, have been found to have better management success (Moffatt and Pless 1983). However, other factors such as intelligence, self-esteem, life experiences, cultural support and ego identity are also deemed important. Very few of these have been investigated, and fewer still were obtained by direct interview techniques with the child as informant.
In a study of insulin-dependent diabetic adults, the
determining factor swaying adherence and metabolic
control was a belief that the individual could engage in
a behavior that would reduce frequency of complications
(Saunders et al. 1975). Since this belief that an active
role seems necessary to achieve a high level of
adherence, it is imperative that individuals and their
families be involved conscientiously in the maintenance
routine. Since a move to complete self care is not
usually advocated before the age of 12 years (Etzwiler
1962, Partridge et al. 1972), the family, and in most
cases the mother as the primary health care broker, plays
an integral part in the maintenance of balance for the
diabetic child.

This life-long development of responsibility may
have some benefits. Partridge et al. (1972) found that
diabetic teenagers felt comfortable with the age of
assumed responsibility (around 12 years) and agreed they
also could take on other non-diabetic related
responsibilities. A control group of non-diabetic teens
felt they were given responsibility too soon. Perhaps
responsibility in the area of their personal diabetic
care paved the way for comfort in responsibility in other
areas. Because little attention has been paid to the
emotional well-being and coping styles of the diabetic,
little is known about the nature of this problem.
Kosub and Kosub (1982) conducted a study assessing the perceptions of stress in diabetic children. Two stress lists were utilized, one a standardized ranking (Coddington 1972) and the other a spontaneously-generated list. Results showed that only stresses "spontaneously mentioned by the diabetic child were relevant for evaluation of psychosocial stress on chronic illness."

The greatest lack of research concerns how children with diabetes view themselves and their condition. These areas of research must be expanded to provide insight to the concepts inherent in a condition which is long term, requires daily attention to management tasks, involves medical complications, and shortens the life span.

CHILDREN'S PERCEPTIONS OF ILLNESS

Research on children's response to illness has followed two lines of inquiry. The first is the study of children's psychological and behavioral responses to disease and illness states and the associated procedures, hospitalizations, and threats of death. The second is the study of children's concepts of birth, bodily functions, illness, and death (Bibace and Walsh 1981).

The early literature on children's understanding of illness causation is dominated by explanations of self-blame, guilt, and punishment (Beverly 1936; Langford
1948; Lynn 1962). Although Brodie (1974) found that only one-fourth of his sample of 408 elementary school children explained illness in terms of self-blame, it is not surprising that children look to personal behavior for explanations of causation. The professional medical sector does not always have an explanation to offer for disease or illness causation. Parental admonitions to avoid specific acts, "or you will get sick" may reinforce self-blame. Warnings to wear proper clothing, remove warm garments when inside, avoid too many sweets, and get enough rest are popular beliefs into which children are socialized. Adults also look to their own actions for causative factors for their children's illnesses (Comaroff and Maguire 1981).

Explanation of causation has been shown to change when children are questioned on theoretical concepts versus tangible illness experiences. In a study by Korbin and Zahorik (1985), children had no explanations to offer on causation a greater percent of the time when faced with an actual illness episode than when questioned about theoretical health states. Children may state that bad weather, inappropriate clothing, or poor dietary habits cause illness. However, when faced with an actual episode of ill health, children may not be able to trace onset to these causative factors. States of health and illness seem capricious, and may involve multiple
factors. Children may be reflecting the acknowledged inability of the popular and professional sectors to explain every illness episode.

A cognitive-developmental framework has provided the dominant perspective for research of children’s views of health and illness. The rationale behind efforts to identify developmental stages is that educational and treatment interventions must consider children’s levels of understanding. The age of the child has long been a benchmark for predicting children’s overall level of cognitive development and conceptualizations of health and illness (Bibace and Walsh 1980; Brewster 1982; Campbell 1978; Millstein et al. 1981; Nagy 1951; Perrin and Gerrity 1981). This framework was adapted from the writings of Piaget (1930), who tied acquisition of physical concepts of time and space to developmental stages, and who defined these stages by the differentiation children make between themselves and the physical world. Piaget believed that all children progress through three major developmental periods, prelogical, concrete logical and formal logical, in a predictable order, which reflects associated maturation.

In the cognitive-developmental approach to children’s acquisition of health and illness concepts (Bibace and Walsh 1980, 1981), children’s responses to a series of questions about illness were grouped according
to Piaget's three stages of cognitive development. Bibace and Walsh also developed two subtypes of explanations in each of Piaget's stages. Bibace and Walsh found that the responses of the children varied in content and sophistication according to their ages. Bibace and Walsh list three significant clinical uses of their data: fostering empathy, facilitating explanation of illness and medical procedures, and bolstering health education (Bibace and Walsh 1981).

A similar approach to the study of healthy children's conceptualization of illness was undertaken by Perrin and Gerrity (1981). They felt that illness can be understood best in the context of development of all children (1984). Therefore, a series of standardized question about illness was administered to healthy children in kindergarten through eighth grade, and their responses categorized according to Piaget's theoretical framework. Results indicated that healthy children systematically progress through illness-related concepts with age (Perrin and Gerrity 1981).

The specific effect of a chronic illness on the developmental process of children remains unanswered. Although it is expected that all children will pass through developmental stages, there are data which indicate that illness itself may affect the rate at which children progress. Bibace and Walsh state that the
"experience of illness has such overwhelming emotional concomitants that the level of conceptualization with respect to the illness is inhibited or regressed" (1981:45). This view seems to be supported by Carandang et al. (1979), who studied siblings of diabetic children and found that these siblings lagged one developmental stage behind siblings of healthy children. They hypothesized that this was due to dysfunctional communication within the family due to the stress of having an ill member.

Evidence contradicting this view is offered by Eiser, Patterson and Tripp (1984), who compared health and illness concepts in diabetic and healthy children. The two groups did not differ significantly in their knowledge of causation of illness, nor in their definition of health, although diabetic children did exhibit a greater knowledge about causation of diabetes in specific. Eiser et al. concluded that the age and the specific illness of the child better predict cognitive levels. They caution that the demands of specific chronic illnesses must be considered when investigating the effect of illness experiences on cognition.

An approach that offers an alternative to cognitive developmental models arose from a study by Bluebond-Langner (1978) with terminally ill leukemic children. Bluebond-Langner found that tangible experiences
determined progression through levels of understanding. Age and intellectual ability were not related to how quickly or how completely a child passed through a stage. Instead, the children accumulated information from experiences concerning their disease, which in turn affected their conceptualizations of their disease and their self-concepts. The children moved from the realization that they had a serious disease, through believing that they were ill but would get better, to an understanding of the chronicity of the condition, to a realization that they were dying. The children needed the information gathered through experience at each stage in order to move on to the next.

Knowledge

Research to assess the knowledge held by diabetic children has focused on two broad areas. The first is to ascertain theoretical and practical information necessary for management procedures. Recommendations for appropriate ages at which children can be responsible for self-care have arisen from these studies. The second area of investigation involves concepts children hold about the causation and implication of the diabetic states.
Several studies have assessed the type or extent of knowledge held by children with diabetes (Collier and Etzwiler 1971; Eastman et al. 1983; Etzwiler 1962; Harkavy et al. 1983) or the knowledge possessed by their parents (Collier and Etzwiler 1971; Eastman 1983; Linn et al. 1980). These studies addressed several areas of knowledge: general theory (Harkavy 1983), problem-solving, skills (urine testing, insulin injection), symptoms (Etzwiler and Sines 1962; Eastman et al. 1983), and nutrition. Results indicated that diabetic children tend to have inadequate diabetic knowledge and skills (Harkavy 1983; Etzwiler and Sines 1962; Ludvigsson 1977; Eastman et al. 1983). The hope is that by recognizing the knowledge base, adherence to prescribed health-sustaining management procedures may be improved using educational means. The assumption is that lack of accurate information leads to lack of compliance. Although this may be a contributing factor, it must always be acknowledged that patients and their families may have a "hidden agenda" or have a different explanatory models.

Age and sex apparently contribute to the assessed knowledge of a diabetic child. Duration of disease was found to have no relation to knowledge in two studies (Harkavy 1983; Collier and Etzwiler 1971). The additional factors of grade level of the child and
educational level of the mother were insignificant in the 
Collier and Etzwiler (1971) study.

Etzwiler and his colleagues have conducted several 
projects with diabetic children. While questioning 74 
children in a diabetic camp (1962) he was concerned that 
although 75% of the children in the 6-7 year old age 
groups could read the results of a urine test, only 50% 
of the 16-17 years olds could tie that information to 
insulin needs. Thus, children may operate on a clinical 
level without the underlying theoretical knowledge. In a 
subsequent study by Etzwiler and Sines (1962) it was 
determined further that many parents also lacked the 
knowledge to handle properly the diabetic state of the 
child.

Collier and Etzwiler (1971) further analyzed the 
kinds of errors made in diabetic care and concluded that 
mistakes in testing for acetone, information about types 
of insulin, dietary factors and symptoms of acidosis were 
most frequent. Misinformation about diet, and 
recognition of imbalance symptoms, plus lack of genetic 
information also were found to be problems in the 
juvenile diabetic population studied by Garner and 

Methodology is a factor that must be considered when 
assessing inadequate levels of diabetic knowledge. The 
questionnaires used to gather information are not always
published in articles, often making it difficult to assess the conclusions drawn from the data. In addition, the children's perceptions of the children were not taken into account, only the factual knowledge that they were able to transmit to the researchers. For example, in the Garner and Thompson study, the majority of children described their diet in a multiple choice questionnaire as consisting of "special foods" instead of a "well-balanced diet that the whole family can use." Children describe management as "rigidly following the rules for control, not engaging in unusual activities, and always asking the doctor before doing anything different" (Garner and Thompson, 1974b:246). This information seems to support the inability of this population to assume self-responsibility for care (Eiser 1985). However, it could be argued that what these children lacked was not the ability to care for themselves, but the vision of themselves as "normal" or having a daily life-style similar to that of their peers. These responses may in fact reflect the reality of the diabetic condition for these children and may not, in turn, reflect a lack of diabetic information.
ANTHROPOLOGICAL MODELS

Juvenile diabetes has not been subjected to intensive investigation in a cultural anthropological framework. Diabetes has been studied from an epidemiological perspective and as a concomitant of acculturation by physical anthropologists and geneticists (Neel 1962, 1982; Eaton 1977; Weiss 1984), but these studies focus on non-insulin dependent diabetes. Two notable exceptions are dissertation work by Sperlich (1982), who gathered data at a diabetic camp to study the development of coping skills by diabetic children and their parents, and a study by Krantzler (1987) which presented problems in case management resulting from cultural conflict.

In the anthropological literature review which follows, two major areas of contribution are addressed. The first is the disease/illness dichotomy, which differentiates an individual’s biological and social selves. The second is medical anthropological models, adapted and developed to conceptualize health and illness beliefs and behaviors which are predicated upon the distinction between disease and illness. These concepts prove helpful in investigating the perceptions and behaviors of diabetic children.
The Disease/Illness Dichotomy

Although patients and healers may share a common cultural background, their assumptions and expectations when dealing with deviations from health may vary greatly. Western physicians are enculturated into a biomedical model, which emphasizes scientific cause-and-effect logic. This is, in part, a result of conceptual models which developed from the Flexnerian approach to medical education; this approach has been very successful at providing explanations for the etiology, pathophysiology and medical treatment of disease states.

However, it has been established that attempts to address health and illness by the exclusive use of a biomedical model is insufficient (Eisenberg 1977; Fabrega 1973; Kleinman 1980). An essential dichotomy between disease and illness has been described by Eisenberg (1977) and expanded upon by Kleinman (1980) and Young (1982b). Patients suffer "illness," physicians diagnose and treat "disease." (Eisenberg 1977:11).

Disease constitutes "abnormalities in structure and/or function in organs or organ systems" (Kleinman 1980; Young 1982b). This is the realm of biomedicine, the predominant medical system in the West. Disease lends itself to objective categorization and laboratory testing. A result of this perspective is the defining of
health by physical and biochemical parameters (Helman 1985). Weight, height, blood counts, heart rate and -- in the case of diabetes -- blood sugar levels which fall within a predetermined "normal" range, define a health state.

Illness is the individual's personal experience of disease. It consists of the "person's perceptions and experiences of certain socially or personally disvalued states" (Kleinman 1980). It is a subjective response, and includes factors such as beliefs in the origin and severity of the condition, concepts of appropriate treatment, and the effect of the experience on personal relationships. Disease and illness domains may overlap, but each must be addressed to assure success in the clinical encounter.

This conceptual dichotomy creates two realities when applied to a chronic illness such as diabetes. Diabetes as a disease state is manifested in the same clinical manner in Africa, Asia and the United States. The same pathology (within the range of accepted human variation) is assumed to be the cause of the disease state, and the same principle of management -- producing acceptable blood sugar levels through insulin injection and a balance of dietary management and exercise -- is the treatment.

The illness component of diabetes takes into account the response of individuals to their condition and the
meaning they attach to the experience. Explanations of why they have this condition, how it affects their relationships with other people, and steps taken to re-establish a healthy state and the changing definition of what is "good health" all are components of the illness perspective. Therefore, diabetes may be interpreted in very different ways by individuals from different cultural backgrounds. This individualistic interpretation of illness also leads to the selection of different treatment options and varying levels of satisfaction with care.

A third dimension is that of sickness. Kleinman (1980) defines the term sickness as encompassing both disease and illness. This definition is contradicted by Young, who defines the term as "the process through which worrisome behavioral and biological signs, particularly ones originating in disease, are given socially recognizable meaning" (1982b:270). Sickness socializes disease and illness, and helps determine accessibility to practitioners, labeling of specific disease, illness states based on economic and social positions, and allocation of responsibility for contraction of the disease (Young 1982b).

Young recognizes the importance of defining sickness in the context of society. These factors are real and operationalized; however, the focus of this study does
not extend to society as a whole. It is aimed at
gathering information from individuals at a specific
point in their lives. These children previously had been
labeled as "diabetic" by medical professionals, and were
obtaining care from the same clinic and practitioners.
Therefore, the "sickness" aspect of diabetes is not
specifically addressed in this paper.

The "Health Care System"

The disease/illness dichotomy becomes particularly
useful when viewed in the appropriate medical sectors.
Kleinman et al. (1978) states that,

Medical systems operate both as cultural
and social systems. Medical systems
constitute systems of meaning and behavioral
norms, but those meanings and norms are
attached to particular social relationships
and institutional settings (1978:85).
Kleinman labels the cultural system as a "health
care system." In any complex society, three distinctive
local arenas are contained within a health care system:
professional, folk, and popular. Each sector is
organized around particular social relationships and
institutional settings. Causation of treatment of ill
health, designation of healer and patient, and clinical
role relationships are defined differently in each of the
three sectors (Helman 1984).
The professional sector embodies professional scientific medicine. In the United States, this constitutes the biomedical tradition. However, this sector also may include indigenous systems which have become professionalized, for example, the chiropractic tradition. Official labeling of a medical condition, i.e. diabetes, and legal sanctioning of the existence of a disease state are obtained through the professional sector.

The folk sector includes non-professional healers, meaning that they are not part of the "official" medical system. The folk sector often is quite large in non-Western cultures, but also exists in Western traditions, especially among ethnic minorities (Chrisman and Kleinman 1983). Since folk healers arise from the traditions of a given society, they tend to share a similar world view with their patients. Their approach often recognizes and integrates all aspects of a patient's life including personal relationships, supernatural beliefs, and physical and emotional complaints.

The popular sector includes people who are ill, their families, and other lay, non-professional people to whom they turn for advice. It is estimated that 70-90 percent of all sickness is managed solely within this domain (Kleinman et al. 1978). The family is the major participant in this arena of health care, with women
being the main providers of care (Kleinman et al. 1978; Mechanic 1978). Certain other individuals also may be sought more often within the popular sector of care. These people include, but are not limited to, individuals who have had previous experience with a particular illness or treatment (Helman 1984). Decisions about seeking care within the professional and folk sectors also are made in the popular sector of care.

Many illness episodes never leave the popular sector. Symptoms may be defined, treatments developed, and satisfactory results obtained without ever venturing outside the opinions and suggestions of this domain. This does not necessarily mean that satisfactory biomedical results have not been obtained, only that individual expectations have been met or that the professional and folk sectors were not viewed as an acceptable solution.

The popular sector plays a major role in the management of the diabetic condition. As will be illustrated later, diabetes is a medical condition requiring the professional sector if the patient is to survive. However, even in the case of this chronic illness, the majority of care remains with the child and family in the popular sector of care.
Explanatory Models

Arthur Kleinman has developed a clinical tool, called the Explanatory Model (EM), to look at the process by which illness is interpreted and treated. EMs are defined as "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman 1980:105). The goal of eliciting EMs is to begin better to understand the beliefs and behaviors of patients and health care professionals to allow for a shared understanding of perspective.

An EM should be elicited from individuals in each of the health care system sectors. Indeed, EMs owe much of their content to the particular sector in which they are couched. Information about etiology, onset of symptoms, pathophysiology, severity and type of sick role, and treatment may be gathered through the EM process (Kleinman 1980).

EMs arising from the popular sector of care are influenced by cultural factors. They may draw upon several belief systems, and are not necessarily consistent or "logical" in scientific cause and effect. EMs held by individuals operating in the Western professional sector of care are influenced by the biomedical model emphasizing single causal logic and
objective measures of disease. Therefore, the EMs of medical professionals most likely resemble the disease model, while those of the patients and their families resemble the illness model.

EMs change over time with accrued experiences. They represent individuals' thoughts and beliefs and may not be consistent within a culture, or even within a community or family. Often, problems which arise in the clinical encounter may be traced to differing EMs. In particular, efficacy may be lost when biomedical professionals treat disease, and their client's EM is composed of illness concerns.

Mutual understanding (but not necessarily agreement) of the personal EMs of patient and practitioner as a result of the clinical negotiation process may help avoid future conflict and non-adherence. Attending to this clinical method, which Ian McWhinney has named the patient-centered method with an aim to "understand the meaning of the illness of the patient as well as to diagnose his disease" (McWhinney 1988), has resulted in higher patient-reported short-term compliance (Stewart 1984).

Young (1981, 1982a) criticizes the explanatory model approach as being too simplistic. He argues that many sets of underlying knowledge determine an individual's statements. This is why the resulting EMs seem complex
and ambiguous. Young states that the EMs could be the product of any one of five sets of knowledge:

(1) theoretical knowledge, which organizes classes from discrete experiences,
(2) empirical knowledge based on the particularities of experiences,
(3) rationalized knowledge which produces a coherent picture in conjunction with previously held beliefs,
(4) intersubjective knowledge; the way information is translated in order to make others comprehend, or
(5) negotiated knowledge, which is gained through interaction with other people (1981:326).

In the face of an illness episode, many types of knowledge are being produced. Thus, the assumption that one gains a clear, concise account of an experience using only explanatory models is unreasonable. Therefore, gathering data which tap several sources of knowledge strengthens research.

This research used the concept of EMs as a foundation for understanding the diabetic condition. Ideally, EMs should be elicited from all participating members in an illness episode. Chronic conditions such as diabetes require daily home care. Since parents are the gatekeepers and caretakers of children, there tends to be a greater interest in gaining the parents' perspective. In the past, the child's view has not been investigated. A child's beliefs about the occurrence of illness, appropriate treatment, and fears about their condition may differ greatly from those of adults. It is
for this reason that the children's perceptions were the focus of this research.

The Health Seeking Process

The popular sector of health care has tended to receive less attention than the professional or folk sectors. As stated earlier, the actions taken within this sector of care determines if help will be sought from folk or professional healers. Noel Chrisman (1977) has developed a model of the health-seeking process, which traces illness behaviors.

The "health seeking process" was developed to be used as a window into the conceptualizations of participants in an illness episode, and may be used to document the natural history of an illness. This model is particularly useful when conducting research in a complex, heterogeneous society such as the United States. Chrisman's model begins with symptom definition and moves through shifts in roles to treatment action and adherence to designated health regimes. All of this movement is mediated by the lay referral system.

The "health seeking process" cannot begin until a deviation from the individuals' normal health state is perceived by themselves or another. This usually is done through a perceived set of symptoms. The manner in which
symptoms are perceived and defined depends on the cultural values of an individual.

Although there is a strong, highly organized and formalized medical system in place in the United States, it is imperative to realize that the majority of people with illness episodes never enter the formal health care system (Chrisman 1977; Kleinman 1980). Instead, they become locked into the lay referral system, which is most often contained in the popular sector of health care. In the lay referral system, symptoms may be defined, treatments developed, and satisfactory results obtained without ever venturing outside the opinions and suggestions of significant others.

The onset of diabetes in children often is very dramatic. It quickly is evident that the child’s health state has deviated from the culturally and historically variable standard of normalcy established by everyday experience (Friedson 1970:285). Although the lay referral system may be utilized extensively before seeking formal medical care, eventually the formal system must be entered. Indeed, this may happen on the urging of a significant person within the individual lay referral system. This lay consultant may then continue to operate by aiding in evaluation of formal care.

In light of the position held by children in American society, unless recognized adults intercede on
their parts, children may not receive care beyond any self-treatment they may institute. The child's "lay referral system" must be activated to implement care.

Information on types and sources of treatment is gathered by the individual through lay consultation and referral. An explanatory model also is constructed during the process of seeking help. Past experiences and available resources determine the chosen treatments and treatment sources. Conditions such as diabetes, which requires long-term management, could lead to consultation with resources in the folk and popular sectors of care. It is for these reasons that seeking the perspective of ill individuals and their lay consultation system becomes important.

The final component in the health-seeking process is adherence to the prescribed regime. It is here that the doctor/patient relationship exerts a strong influence. A factor related to the probability of seeking a physician's care is the degree of congruence between the patient's health beliefs and those of the doctor (Freidson 1970). It follows that the continued relations with a particular health professional, and the likelihood that medical advice will be followed, also depends in part on congruence of beliefs. In the case of children, it is the congruence of the parental and professional
belief systems that initially determines the mode and timing of care.

Chrisman's model indicates that investigation and conceptualization of illness events must move beyond the clinical encounter. The health seeking process is dynamic, and is driven by beliefs and behaviors arising from cultural and social factors. Elicitation of these factors would lead to better understanding between patient and healer, and would result in higher rates of adherence.

Chrisman (1977) states that his construction of the health seeking process does not integrate behaviors of chronically ill individuals who work to maintain a newly defined state of health. To begin to understand concepts of health and illness held by particular individuals, the distinction between illness, which patients experience and define, and disease, which physicians in Western cultures are trained to recognize and treat, must be clarified.

**CHRONIC ILLNESS AND THE FAMILY**

The family plays a major role in structuring and negotiating health care. Thus, whether the child is healthy or chronically ill, the family helps construct social reality for the children and themselves.
Smilkstein defines the family as a "homeostatic system; change in one part could produce a psychophysiological reaction in another" (Smilkstein 1980; 143). Thus, for research purposes, the family may be viewed as a dynamic unit constantly affected by stressful life events. It follows that illness and hospitalization of children have a great affect on family function. The impact path of chronic illness on the family is multi-directional. It may be financial, social, behavioral, somatic or mental (Drotar and Bush 1985).

It is within the context of the family that disease becomes illness, and health and illness care is delivered. This popular sector of care has vast research potential, but is not often utilized as a research setting. Self-care, "the basic level of health care in all societies," (Dean 1981;673) is the initial and primary mode of care for acute and chronic illness. However, it is this particular set of health and illness activities of which we know the least.

Past literature has recognized the cultural system of the family and has focused on eliciting and/or examining the parents' and patients' view of their illness experience (Anderson 1981; Kleinman 1978). Seventy to ninety percent of all illness episodes are dealt with outside the formal health care system. The family is a major provider of this health care (Hulka et
al. 1972). The mother of a diabetic child explains, "You become your child's primary physician while the physician acts as consultant" (Ducat 1983:5). It is for these reasons that comprehension of the families' view of illness is so important.

The family is called upon both as a provider of care and as a deciding force in the management of therapies inside the home (Anderson 1981). Daily management of diabetes requires the coordination of insulin injections, diet, and exercise. Either the diabetic child must be isolated in these activities, or the entire family must develop diets and schedules that accommodate necessary management tasks.

The primary goal of parents with chronically ill children is to construct a sense of normalcy. In a study by Anderson (1981) in which the explanatory models of parents with chronically ill children were gathered, and naturally-occurring encounters between parent and child were observed, the parents of ill children often described this normalization process as a coping mechanism. An effort was made to minimize the deviant label regarding the child. Family activities, time tables, and diets were altered to integrate the ill child's needs. However, closer examination revealed that parents' verbal accounts of attempted normalcy conflicted with their everyday routine. Parents' understanding of
their children's conditions as based on the biomedical model determined the construction of the illness experience. Restrictions on activities, independence, and diet were common guidelines set by parents. This information becomes extremely important when developing a treatment and management program for the home. The family's explanatory model of health and illness contributes greatly to compliance and satisfaction with care.

When assessing the effect of family stress due to chronic illness, it is wise to consider the variable factors in chronic illness. Although stress may increase family cohesiveness, it also may act as a catalyst towards disintegration of the family group (Masters et al. 1983). The diagnosis of chronic illness may come as a shock, and coping mechanisms must be developed within the family to permit group survival. It has been suggested that diseases with a genetic component may introduce feelings of guilt in the parents and provide stress if a decision is made to have no more children (Masters et al., 1983). The divorce rate in families with a child having a disorder with a high-recurrence rate is similar to the national average of parents with so-called healthy children. However, Begleiter, Burry and Harris (1976) note that the divorce rate for parents
with children having nongenetic and low-recurrence probability diseases is lower than the national average.

Siblings also may be at risk of experiencing a number of negative feelings associated with chronic illness. Siblings may feel embarrassment, guilt, envy, and resentment. They also may feel abandoned when an ill child is hospitalized, because the parents spend a good deal of time away from home (Featherstone 1980). Siblings of ill children may also tend toward irritability and withdrawal (Lavigne and Ryan 1979).

Crain et al. (1966) found that siblings of diabetic children were the family members at greatest risk of experiencing illness-related stress. Levels of illness conceptualization among siblings of diabetic children were studied within a Piagetian framework by Caradang et al. (1979). Results showed that, not only was the children's ability to conceptualize illness related to their cognitive level of development, but also that cognitive levels were less advanced for siblings living with a diabetic child. The illness conceptualizations of children who were formal operational thinkers and had an ill sibling were most affected. The authors suggest that an absence of abstract information related to children in lieu of the many physical facts involved with diabetes causes this developmental lag (Caradang et al. 1979).
Another theory on sibling development implicates the coping style of mothers, who choose to focus only on short term tasks and current physical conditions, thereby forcing a pseudo-normal routine. This approach may mediate anxiety felt by a parent. In addition, adolescent siblings may choose not to focus on their vulnerability to a chronic condition, nor the possible vulnerability of their future children, since many conditions carry a genetic component. This may retard the development of their conceptualizations of illness.

Duration, severity, projected outcome, and visibility affect family functioning in different ways. However, it is clear that in the case of chronic illness, the family always will experience change. It is for this reason that effective clinical work with chronically ill children requires a focus on the impact of illness-related stress on the entire family, and a realization that coping styles are dynamic and will vary with changing stages and severity of physical conditions (Drotar 1981:211).

PURPOSE OF THE PRESENT STUDY

Medical anthropological studies have focused on describing the medical system of a particular society, or on a sector of that system (Pelto and Pelto 1978).
Anthropologists now are utilizing the tools and perspectives developed in the study of small, traditional cultures, in the studies of complex, industrialized societies.

A large sector of the population, rich with information and deserving of attention to their emic perspective, is children. In the United States, children generally are considered incompetent to carry out significant tasks that they might perform as a matter of course in other societies (Bronfenbrenner 1976). Children are often disregarded as informants. They are believed to possess limited experience with, and restricted access to, health and illness resources.

Medical anthropologists have a strong interest "in the personal interpretation of and response to illness, the search for help, communication between patient and healer and the assessment of outcome" (Chrisman and Kleinman 1983:569). The personal interpretation of the child is the focus of this study.

An underestimation of the true abilities of children, and concern about the difficulties inherent in communication with children, have resulted in a lack of research examining the world of the child from his or her own vantage point (Tammivaara and Enright 1986). This research attempted just that - to gather data from diabetic children in an exploratory fashion - "... to
grasp the native's point of view, his relation to life, to realize his vision of his world" (Malinowski 1922:25). Although contact was made with parents and health care workers, only the children were formally interviewed.

Children with chronic illnesses have a different set of early experiences, and are exposed to more medical information and experiences than their "healthy" peers. How does this affect their perceptions of health and illness? Are these children socialized into medical utilization patterns that reflect the "chronicity" of their condition, or do they utilize a model based on "acute" episodes of illness?

Juvenile-onset diabetes is a chronic illness having medical and psychosocial implications. It is a condition requiring daily management, almost wholly contained within the popular sector of health care. These daily management procedures not only help to maintain biological health, but also contribute to the child's social reality. The knowledge about health and illness states, daily management procedures and actions taken in response to episodes of ill health, and coping styles, in short, the translation of the disease of diabetes to an illness experience all are mediated by the popular sector of health care. Clues to the thoughts and expectations held by diabetic children can be explored through explanatory models. The actions taken in response to
illness episodes may be traced through the health-seeking process. The thoughts, actions, and expectations of diabetic children are the focus of this research.
CHAPTER III

METHODOLOGY

Three sets of open-ended interviews were administered to 26 diabetic children between the ages of 6-12 years. The interviews tapped the children's perspective on broad categories of information about diabetes, such as labeling, etiology, pathophysiology, symptomology, management of diabetic and non-diabetic illness episodes, coping strategies, associated stresses, and health-promoting activities. For the purpose of this research, states of hyperglycemia and hypoglycemia will be referred to collectively as "imbalance episodes."

SAMPLE

Patients were sampled from a diabetic out-patient clinic at a university medical center that serves all of north-eastern Ohio. The children were seen by one of four primary health professionals for regularly-scheduled check-ups. A list of all children enrolled in the diabetic clinic was obtained from the hospital. The
research sample was selected to include all children, 7-12 years of age. An additional criterion for inclusion in the study was that the child be diagnosed with diabetes for at least six (6) months at the time of the initial interview. Children having physical problems (e.g. deafness) or whose families had requested exclusion from hospital projects (as noted by the health professionals) were not contacted.

A total of 56 letters were sent to parents of children fulfilling the research criteria. The letter explained the study and informed the parents that they would be contacted by telephone to obtain verbal permission and arrange an interview time. Each parent was telephoned approximately a week before their appointment. If verbal permission was granted, the time for the initial interview was set. Seven of these families could not be contacted due to a change of residence or disconnected phone service.

Of those who were contacted, reasons given for not participating in the project were: [1] parents or children were not interested, stating that they had already spoken to researchers several times (n=5), [2] the child had summer plans which included extended time in other cities (n=4), and [3] a case in which a single father had two diabetic children and felt he could not deal with scheduling problems. Three families who had
agreed to participate were not included due to continual scheduling problems, and an additional ten families were not contacted after five or more attempts.

The final sample consisted of a total of 26 children, resulting in a participation rate of 56.5% (based on the original 56 letters sent). All of the children completed the study, with no sample attrition. The sample consisted of 11 males (42.3%) and 15 females (57.7%), with 6 Black (23.1%) and 20 White (76.9%) children. The average age of a child at the time of the initial interview was 9.8 years (median age = 10 years). The average age at diagnosis was 5.4 years. The amount of time the children had been diagnosed as having diabetes ranged from six months to ten years. The median number of years the children had been diagnosed as diabetic was 4.6 years. This information was unavailable for one child. Socio-economic status could not be determined consistently, since parents were not interviewed and medical charts often listed no information on income or occupation. At times, only the name of a company at which a parent was employed was listed in the medical charts, and this was done for insurance purposes.

Information on household composition was gathered from each child, and verified with medical charts when possible. In 65.4% of the cases (n=17), the target child
lived with both biological parents. Five children (19.2%) lived with only their biological mothers and the remaining 4 children (15.4%) lived with their mother and an additional relative or step-father/boyfriend. No household had more than 3 children. One child was an only child. Ten children (38.5%) were first born, and fifteen later born.

INTERVIEWS

The data were generated from structured, open-ended interview guides. The guides were based partially on the concept of explanatory models (EMs) developed by Kleinman (1980), and Chrisman’s health-seeking process (1977). Kleinman’s EMs are used to elicit "notions about an episode of sickness and the treatment employed by those engaged in the clinical process" (Kleinman 1980:104-105). Chrisman’s health-seeking process is a model which traces the natural history of an illness episode. All interviewing was done by the principal investigator or a graduate student who had been trained for this particular study. The graduate student conducted 10 initial interviews, 33 weekly interviews, and none of the follow-up interviews. A reliability check was conducted to assure a range of congruence in the data gathering stage and data coding stage of the research.
The data were gathered in three separate sets of interviews: (1) an initial interview, conducted in the clinic during a scheduled diabetic visit, (2) weekly interviews, conducted via the telephone at an agreed-upon time and, (3) a final interview, also collected in the clinic at the next scheduled visit. Clinic appointments usually were scheduled every three months. However, some children did not return for six to nine months. The weekly interviews were conducted by telephone, beginning after the initial interview and continuing until the final clinic visit. Additional demographic data also were gathered from each child's medical chart.

At the completion of the study, 26 initial interviews, 339 weekly interviews, and 26 final interviews had been collected. The average number of weekly interviews was 13 per child and the median was 11. The data from the three interviews were primarily qualitative. Descriptive statistics were applied using SPSS, and spatial diagrams were created using multidimensional scaling. The following is detailed information concerning each interview:

**Initial Interview**

The initial interview was conducted when the child came to the clinic for a regularly scheduled appointment.
Before conducting this interview, written consent was obtained from the accompanying parent and from the child. If a child declined consent, as happened in one case after an extensive wait to see the physician, the interview was abandoned.

The elicited data in the initial interview (see Appendix I) included:

1. Labeling of the condition: The term "diabetes" was not utilized in the interview until the child specifically named the condition. This was done to avoid presenting the child with a label, and to determine if the children employed a label other than "diabetes." The children were asked the following questions to elicit their labeling term:

   "Why are you visiting here?"

   "What do you call [the reason that you come here to the clinic]?"

2. The disease process of diabetes: Questions were aimed at gaining the children's view of the biological process involved in diabetes, and how this process affected their bodies. Each child's explanation of their parents' and physicians' description of pathology was also elicited. The following questions were asked to gain this information:

   "What is diabetes?"

   "How does it [diabetes] work?"
"How does the doctor say it works?"

"How do your parents say it works?"

3. Etiology of diabetes: The child's view of the causation of diabetes and why the condition manifested itself at a particular time in the child's life-cycle was elicited with the following questions:

"What causes diabetes?"

"Why do you think it started when it did?"

4. Symptomology of diabetes: The physical and mental symptoms experienced by the child were elicited. The child also was asked, by describing specific symptoms and feelings, to explain how they knew when they were in imbalance. They were asked:

"What does diabetes do to you?"

"How do you know when you feel bad?"

5. Perceived limitations and fears associated with diabetes: Thoughts on restrictions experienced by the children (i.e. diet), limitations (over-night stays at friends), and fears (complications) were elicited using the following questions:

"Is there anything you really don't like about this condition? Is there anything that frightens you?"

"Is there anything you would like to do that you can't?"
6. Perceived reactions of siblings and friends to the diabetic condition: The children were questioned regarding the visibility of their condition and the perceived thoughts of their siblings and friends. They were asked:

"Can other people tell that you have this condition [diabetes]?"

"What do your brothers and sisters think about your condition [diabetes]?

"What do your friends think?"

7. Management procedures: The children were asked what daily tasks they needed to perform in response to their diabetes. Information on diet, insulin, and blood or urine tests was gathered. The child’s beliefs about the effectiveness of these procedures were elicited. They were also asked about possible alternative actions to feel good. The following questions were used to elicit this information:

"Are there certain things you have to do to stay feeling good?"

"What things do you have to do daily because of this condition [diabetes]?

"Have you tried both blood and urine testing?"

"Do you prefer one or the other?"

"Do these things make you feel better?"
"Do you think that they help you?"
"What would make you feel better?"

8. Severity and longevity of the diabetic condition: The children were asked their views on the severity of diabetes. A comparison was posed between the perceived severity of diabetes and a cold or chicken pox. Perceptions of the most serious condition the children experienced, and their perceptions on the length of time the diabetic condition would last, also were explored. They were asked:

"How long will this condition [diabetes] last?"
"Is this a bad condition? Worse than a cold? Worse that chicken pox?"
"What is the most serious sickness you have ever had?"

Weekly Interview

The structure of these interviews was based on the health-seeking process as developed by Noel Chrisman (1977). Data were gathered weekly by telephone, beginning after the initial interview and continuing until the date of the final interview. These interviews tapped the child's perceived health over the study period on a regular and frequent basis. The natural history of illness episodes precipitated by diabetic imbalance and
non-diabetic related illnesses were traced through the stages of symptom definition, lay consultation, and treatment action. Health maintenance strategies also were elicited. By speaking with the child weekly, it was often possible to question them within hours of an imbalance episode. This mitigated problems inherent in retrospective questioning. Areas investigated included (see Appendix I):

1. Practices undertaken to ensure good health: The children were asked:

   "How have you been this past week?"
   "What did you do to stay healthy this week?"
   "Did you do anything new?"

2. Diabetic and non-diabetic illness episodes experienced that week: If the child indicated that they had been ill, the following question was asked to elicit indicators of ill health:

   "How did you know that something was wrong?"
   "Could anyone tell that you were not feeling well?"

3. The hierarchy of resort in response to illness episodes: The children were asked about the first, second and third responses to illness episodes:

   "What was the first thing you did [in response to ill health]?"
   "What was the next thing that you did?"
4. The involvement of others (parents, sibling) in recognition of ill health or as lay consultants: After the children listed each response to their illness episode (#3 above), they were questioned as to who made the decision or advised a specific action. The following questions were included to determine if these children acted independently in matters of ill health:

"Did you tell someone [about being ill]"

"Did someone tell you to do that?" [to take a specific action listed in the hierarchy of resort]"

5. Indications that the illness episode had been resolved: The children were asked to describe the factors which indicated their illness episode had been resolved and that they had returned to a state of health. They were asked:

"Did you get better?"

"How could you tell [that you were better]?"

6. Possible events or behaviors which precipitated both diabetic and non-diabetic illness: The children were questioned about possible concomitant behaviors that might have precipitated their imbalance episode or state of ill health as follows:

"What were you doing just previous to this episode?"
7. The child’s view of why the illness episode occurred: As a follow-up to question #6 above, information was elicited from the children as to why this particular episode occurred, and if there was a possibility of a similar episode in the future. Using the following questions, further information was obtained as to the child’s view of illness causation, the effect of their actions on their health, and possible preventative actions for the future:

"Do you have ideas about why this [episode] might have happened?"

"Do you think this might happen again?
Why or why not?"

Final Interview

The third interview was conducted in the clinical setting at the next scheduled medical appointment, which took place 3 to 9 months after the initial interview. This interview allowed for re-exploration of many areas introduced in the initial interview. This also allowed a comparison of answers over a period of time. Data elicited included (see Appendix I):

1. The children’s involvement in and perception of diabetic summer camps: The children were asked the following questions about attending camp:
"Have you attended diabetic camp?" "When?"
"Did you return?" "Why or why not?"
"Who made the decision that you would go to camp?"
"Does it help you?" "Why?"
"What did you like best about camp?"
"Does it make a difference being around other diabetic kids?"

2. Concepts of self: These questions were designed to explore how the children viewed themselves as diabetics, and in comparison to non-diabetic children. The children were asked the following questions:

"Does it make a difference being around other diabetic kids?"

"Do you feel different because you have diabetes?"

3. Changes in family functioning due to diabetes: The following questions were designed to elicit information on necessary dietary and schedule adjustments:

"Is there anything your family does differently now than they did before you found out that you had diabetes?"

4. The function of insulin: The following question was included to determine if the children had a working
knowledge of insulin function or just viewed it as a substance they were told they needed daily:

"How does insulin work?"

5. Management procedures—including use of insulin and blood or urine tests: Management procedures were again explored; however, additional details were included regarding insulin administration and daily urine or blood tests. Information about the number of insulin injections, dosage and type of insulin, self administering of injections, type of tests conducted, frequency of tests, and the individual responsible for the administration and interpretation of these tests was elicited. The children were asked:

"How often do you take insulin?"

"What type [of insulin] do you take?"

"Does someone give it to you or do you do it yourself?"

"What kind of tests do you do?"

"Who does them?"

"Who reads [interprets] the tests?"

6. Perceived necessity of clinic visits and satisfaction with those visits: These questions explored the children’s understanding of the need for scheduled clinic visits, and shed light on the children’s views of their personal condition of health (e.g., Do I
really need this much attention for my particular condition?). The following questions were asked:

"Do you think you need to come to the clinic when you do?"

"Does your [health professional] spend enough time talking with you?"

"Do you understand what he/she say?"

7. Parental and sibling reaction to imbalance episodes: The following questions were asked to elicit the roles of other family members concerning diabetic reactions:

"How do your parents react when you have a reaction or feel bad?"

"How do your brothers and sisters react?"

8. Reasons for hospitalization: This information was gathered from the children and checked with hospital records when possible. The children were asked:

"How many times have you been in the hospital?"

"What were the reasons that you were hospitalized?"

9. Lists of stresses: The following questions were asked to elicit two stress lists from the children. The first allowed them to list the top three stressful things in their life, and the second pertained only to stress associated with diabetes:
"Could you list the top three stressful things in your life?"
"Could you list the top three stressful things having to do with diabetes?"

10. Benefits of the diabetic condition: Perceptions concerning the positive aspects of living with the diabetic condition were elicited using the following questions:

"What is the best part about being a diabetic?"
"What are your plans for the future?"

The majority of the data from the three interview were qualitative. Descriptive statistics were generated using SPSS. Multi-dimensional scaling was utilized to analyze illness episodes elicited in the weekly data and limitations associated with diabetes elicited in the initial interview.

The methodology of several open-ended interview guides was well suited for this study. Several parents commented that their children enjoyed these encounters, looked forward to the weekly phone calls, and gave information to the researchers that was not shared with them. The interview process produced insights not accessible through a standardized, precategorized survey instrument. The danger inherent in developing precategorized questionnaires was discussed in the section on diabetic children’s perceptions of stresses.
1 Permission to pursue this research was provided through the University Hospitals Institutional Review Board for Human Investigation, the Pediatric Diabetic Unit, and Case Western Reserve University’s Human Subjects Board.

2 It could be argued that lack of a telephone might indicate a lower socio-economic status. Since minority groups often suffer lower SES, the fact that seven families could not be reached due to a lack of a telephone or a recent relocation, may have biased the sample against minority or low SES groups.
CHAPTER IV

RESULTS

The responses given by the children during the interview process are organized into three major sections. The first section will consider the children’s knowledge of diabetes as a medical condition, their beliefs about etiology and pathophysiology, and the means by which they acquire this knowledge. The second section examines the management skills required by the diabetic condition. Three areas of management were examined: the children’s involvement in daily tasks to maintain diabetic homeostasis, responses to imbalance episodes, and actions taken to achieve health. The question of how knowledge of the disease entity is related to illness management skills also will be considered. The third section will focus on the stresses and limitations experienced by the children and their emerging perceptions of self as they cope with the daily reality of a chronic illness.
RESULTS-KNOWLEDGE ABOUT JUVENILE DIABETES

"They are always telling me, "It's O.K., you're not going to die," and it keeps coming up that the pancreas stops working so I have to regulate what I eat and check my blood."

--- 12 year old diabetic child

Assessing an individual's knowledge of diabetes is important for two reasons. First, successful patient education, a fundamental part of the initial diagnosis and treatment of diabetes, is dependent upon knowledge states. Second, it is hoped that an understanding of the effects of imbalance states and how to avoid them will promote greater adherence with diabetic management tasks. The children were questioned about underlying concepts they used to explain and manage their diabetic condition. The children's perceptions were elicited in the areas of labeling, etiology, pathophysiology, and management of diabetes.

The term "diabetes" was not utilized in the interview until the children volunteered the word. This was done to avoid biasing the children towards a particular term, since the children's choice of labeling was of interest. An attempt to elicit the term was made by posing the question "Why are you visiting the clinic?" The majority of the children (n=18, 69.2%) did not
immediately mention diabetes even though the clinic is specifically a diabetes clinic and the children were all there for their regularly scheduled check-ups. The children first stated that they were at the clinic for a "check-up" or to see a specific health care professional. These responses set the stage for the general attitude that many of the children conveyed that diabetes is a condition simply needing vigilance. Clinical visits were seen as part of the diabetic routine, more remarkable for the associated treats such as a trip to the hospital cafeteria or a visit to a city museum than the associated medical implications. The children knew the clinic routine well and would, for example, inform their parents that they still had not been weighed by the nurse, or were waiting for a blood check.

Six children specifically used the word "diabetes" in their response, "I had to get a check-up for diabetes," "to check if everything is going o.k. with diabetes" or "I've got diabetes." Two additional children listed elements associated with the diabetic state, "to check my sugar and ask questions about how high or low it is" and "maybe to get the insulin lower or higher."

If the children did not immediately mention the word "diabetes" they were further questioned until a term was elicited. Questioning the children about why they needed
a check-up or why checking sugar levels was important was successful in eliciting the label diabetes. One child was very descriptive, but did not cite the word "diabetes" until she went through a series of questions:

Interviewer: Why are you visiting here?
Child: For a check-up.
Interviewer: What do you call the reason why you come for a check-up?
Child: To take a blood test, check ears and mouth. The doctor put a band-aid around my toe and said to keep it clean and dry, and she talks to my mother.
Interviewer: Is there any reason the doctor checks you out?
Child: I don't know.
Interviewer: So you just come in for a regular check-up?
Child: Uh huh.

This child went on to explain that she enjoyed the hospital but hated shots. When asked why she had to have shots, she first responded that she didn't know. The conversation continued with the child stating that she had shots when she comes to the hospital for emergencies. She listed diabetic symptoms such as stomach pain, constant urination, and poor muscle coordination, and even listed specific medical specialists. Finally, while describing special foods she stated, "I can't eat sweets but I can eat some. The news [television] said diabetics could eat one sweet a day. I like especially chocolate candy bars, but I don't like coconut." The interviewer replied, "Oh, so are you diabetic?" When the child stated that this was true, the interview continued.
The children never spontaneously referred to their condition as anything but "diabetes." However, when asked if there were any other names or labels for diabetes, two children, both black, offered the term "sugars." Two other children stated that it is when you "can’t have sugar" or elaborated by explaining that the school kids described him as "the kid that can’t have sugar." The link between the folk term "sugars" and the dietary restriction on sweets which is a focal point of conceptual organization is obvious.

Etiology and Biology of Diabetes

First my great grandmother had it, then dad caught it, then I caught it. I think my great grandmother passed it on because she had arthritis with it and arthritis is catching.

----- 8 year old diabetic child

When a diagnosis of juvenile diabetes is made, much information must be processed quickly and many new tasks must be learned. Some of these tasks, giving injections in particular, usually are only legitimately practiced by medical professionals. This skill in particular, falling outside the realm of usually prescribed patient skills, may increase anxiety levels in children and their parents.

Although parents and children are interested in etiology, management skills are given educational
precedence. This may be especially so since etiology is not fully understood in the professional medical sector; and management skills, the crux of daily survival, are more urgent. Consequently, children may learn about the biological effects of diabetes before they understand the factors related to onset and causation of the condition.

When asked what caused their diabetes, many of the children (n=11, 42.3%) simply stated that they did not know. Since several major theories of causation have been proposed, as discussed in Chapter 2, and no conclusive etiology for diabetes has been determined, this response is not necessarily a lack of knowledge, but may be an accurate reflection of current knowledge available about diabetes etiology.

The remainder of the children’s responses covered the gamut of proposed theories. The next largest category of response included some form of body malfunction (n=5, 19.2%), such as, "It’s just when the pancreas doesn’t work." The next group of responses involved eating too much sugar or starch (n=3, 11.5%), followed by germs or viral agents (n=2, 7.7%), and heredity (n=2, 7.7%). Two miscellaneous explanations include a child who specified that "nobody knows yet" and another who stated, "God made me have it in case we have a war, I can’t go and die." This response was particularly interesting since this child had a diabetic
mother and sibling. This information was provided by her grandmother who presented the diabetic condition as an advantage and protection against greater dangers. One child did not respond to this question.

Changing scientific theories with multiple causal components were reflected in the children's response patterns between the initial and the follow-up interviews. Although the actual percentage of responses in the categories remained essentially stable, half of the children (n=13, 50%) changed their answer in the follow-up interview (Table 1). Only five of these thirteen children altered their response to include, what was subjectively judged by the investigator (indicated by a * by the responses in the table), to be more biomedically-oriented information. It is difficult to judge if these changes in responses reflect an increase in knowledge over time, or simply confusion in an area which has no definitive answers.
Table 1 - What causes diabetes? – Children (n=13) who changed their answers

<table>
<thead>
<tr>
<th>Initial Interview</th>
<th>Follow-up Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Don’t know</td>
<td>The part of my pancreas that makes insulin stopped working</td>
</tr>
<tr>
<td>2. Don’t know</td>
<td>A germ</td>
</tr>
<tr>
<td>3. God made me have it so I can’t be in a war.</td>
<td>When you don’t take care of yourself. When you eat too much sugar.</td>
</tr>
<tr>
<td>4. Heredity</td>
<td>Pancreas stops making insulin</td>
</tr>
<tr>
<td>5. Not enough sugar in the body</td>
<td>I don’t know</td>
</tr>
<tr>
<td>6. When the pancreas doesn’t work</td>
<td>I don’t know. It doesn’t produce insulin.</td>
</tr>
<tr>
<td>7. When the pancreas doesn’t work</td>
<td>Nothing really causes it. You just develop it.</td>
</tr>
<tr>
<td>8. I don’t know</td>
<td>Run around in the sun. Eating too much sweets</td>
</tr>
<tr>
<td>9. Eat a lot of candy and stuff</td>
<td>When your pancreas stops giving insulin.</td>
</tr>
<tr>
<td>10. I don’t know</td>
<td>I don’t know. All I know is the pancreas doesn’t produce insulin, I have to inject it.</td>
</tr>
<tr>
<td>Mom knew I had something so that’s why I went to the doctor.</td>
<td>Some can be controlled by diet, usually adult diabetics.</td>
</tr>
<tr>
<td>11. I don’t know</td>
<td>First my great-grandma had it then dad caught it, then I caught it. I think great-grandma passed it on because she had arthritis with it and arthritis is catchy.</td>
</tr>
<tr>
<td>12. I’m not sure but I think mom said that everybody has insulin, but I don’t.</td>
<td>I don’t know</td>
</tr>
<tr>
<td>13. (did not answer)</td>
<td>I don’t know</td>
</tr>
</tbody>
</table>
When questioned as to why the condition presented itself when it did in the child's life cycle, 10 children (38.5%) responded that they did not know. Other responses included the idea that it was "inevitable" or due to hereditary factors, such as a relative who had the disease (n=4, 15.4%); or that the child was young and vulnerable to germs (n=3, 11.5%). Seven children listed a series of symptoms, for example, "I just started going to the bathroom a lot" or "I just got sick." One child offered a very detailed description, "My mom and I have our own ideas. When I was four years old I got into a syndrome and had the flu seven times in a row. After all those sicknesses, my body broke down." This explanation does include a current biomedical observation that onset of diabetes often follows a viral infection of some kind.

When asked "How does diabetes work?" the children often used the words "pancreas" and "insulin." Instances in which both these factors were mentioned numbered 11 (42.3%). All other explanations utilized factors inherent to diabetic management, such as blood or urine testing, sugar and diet restriction, and the need for daily shots. One child, who readily admitted that she did not know what caused diabetes, explained how diabetes worked by rattling off acceptable blood glucose levels, "if you eat a popsicle and you're at 180 you would probably get to 400." She went on to explain that the
lowest she had been was 20, and once she hit 480 after
eating two popsicles. Other examples of responses in
this category were, "You can’t have sweets and you need
to watch yourself real good," and "The thing that makes
insulin doesn’t when you are diabetic and that’s why I
have the shots."

The children’s answers taken as a whole present the
diabetic condition in two ways. The first is a disease
orientation, and is the more personally threatening of
the two. Diabetes is viewed as a serious medical
condition which, if unchecked, could quickly result in
death. These children realize that a specific part of
their body, the pancreas, does not function properly.
This necessitates daily diabetic management procedures.

The second orientation focuses on these very
management tasks. Children learn that the key to
maintaining a healthy state is to vigilantly perform
management tasks. The children speak about the
regulation of blood sugar levels and of responses to
symptoms of diabetic imbalance. This orientation is less
threatening, in part, because the children can actually
take control of their health and illness states.

The concept of insulin injections may connect these
two orientations for the children. Injections are a
daily reminder that a part of their body has gone amiss.
Regulation of food and exercise are recommended health
maintenance strategies for all people, but the need for insulin injections is an indicator of a specific disease entity.

The two orientations of a threatening disease and a manageable illness are not mutually exclusive. Children formulated their answers to the research questions according to any number of stimuli. Factors which might influence their answers may include their knowledge base, a personal illness experience, the experience of a friend or family member with diabetes, or a long period of good health.

Sources of Knowledge

"My mom knows what to do 'cause my dad had it before me."

--- 7 year old diabetic child

The children also were questioned about the explanations of diabetes pathology offered by their parents and doctors. Not surprisingly, the majority of these children (n=21, 80.8%) had no knowledge of diabetes prior to diagnosis. Four of the children claimed some previous information, gained from a parent or sibling with diabetes. Those who had an additional family member who also was diabetic theoretically could have possessed knowledge regarding the condition. However, if it is a parent who has diabetes, eating choices and schedules are
accepted as part of the home routine, not as a result of diabetes management. Although an exchange of information might take place in the home previous to diagnosis, this could act as a benefit or hindrance, depending on the parents’ attitudes towards the condition and their level of diabetic control.

When asked who first explained diabetes to them, 17 (65.3%) listed a health professional. An additional 4 children (15.4%) listed their mothers; 2 (7.7%) said they could not remember; and 1 (3.8%) listed both parents. Two of the children (7.7%) stated that nobody explained the condition to them. Written materials were cited as an alternate source of information; “I learned from reading books and pamphlets mom gave me. When I was younger I wanted my parents to explain but when they tried I couldn’t understand.”

The children’s responses of explanations gained after diagnosis reflected varying experiences with health professionals, such as confusion with professional terminology: “I don’t really remember. There were a lot of technical words and stuff, but I don’t really remember them.” and “They explained it about the same but used larger words. They probably explained it better than I do.” One child specified a nurse clinician as a particularly useful source of information by stating, “She gave me the real information. The other doctors,
the ones that diagnosed it just said it wasn’t too bad. She was the one who really explained it." Five of the children (19.2%) said their doctor never explained this to them.

When questioned about their parents’ explanation of diabetes, eleven of the children (42.3%) stated that their parents never explained the condition to them. Two additional children stated that a diabetic relative offered the first explanations: "My dad has diabetes. He says it’s just something you can never get rid of." or "Mom is a diabetic. She got a book with tapes and pictures and told me." The children told of parental explanations which were reassuring, but also stressed management procedures: "They are always telling me that it is o.k., I’m not going to die, and it keeps coming up that the pancreas stops working, so I have to regulate what I eat and check my blood," or "This will always be with you until they find a cure – so you have to take shots and blood tests every day." Perhaps descriptions about management are more easily offered to children as a concrete explanation for diabetes. As stated earlier, diabetes is a complex condition and there is a lack of specific scientific explanation for the condition.

The chronicity of diabetes was explored through responses to the question, "How long will this condition last?" Four children (15.4%) stated that they did not
know. The remainder of the children (n=22, 84.6%) indicated that diabetes is a long-term illness, voicing terms such as "forever," "until I die," and "all my life." Eight children (36.4%) added the stipulation that the condition would last only until a cure was discovered. The possible cures proposed included insulin pumps (which technically would not be a cure, but an advancement in management of diabetes) and pancreas transplants.

While long-term progression of the disease was recognized in that the children listed complications such as blindness and amputation, the children kept a positive view reflected in their perceptions of the manageability of diabetes as discussed below.

The second, and greater percentage of response highlights the flow of information in the opposite direction. Children expressed having many thoughts and feeling about diabetes. They were pleased to be able to share that knowledge. The children felt it was helpful to others to know about them and their life with diabetes. Expressions such as "Now you know what we feel like. You didn't ask the doctor," "Now the doctor will know what we know," "It will help other kids," "It is helpful for other people to know (about diabetes)," and the most confident response - "I know more about diabetes than anyone else I know," revealed that the children
realize that they are the individuals living with the diabetic condition, and hence have access to experiences and information that may be new to other children. These children felt their perspectives and behaviors were very worthwhile, and should be shared.

**UNDERSTANDING OF MANAGEMENT**

While diabetic children are necessarily involved in management tasks, they do not always indicate that they understand the underlying pathophysiology that necessitates these actions. This reflects the reality of a chronic condition in which health and survival are dependent on daily management of blood sugar levels. The educational focus on management during the initial diagnosis and the knowledge reinforced in the popular sector are centered around management tasks. The subsequent sections detail responses concerning the management tasks of insulin injections, blood or urine tests and diet.
Insulin Injections

"Insulin chops up sugar like Batman!"

---- 7 year old diabetic child

The children were asked, "How does insulin work?" Responses are listed in Table 2. Eight children (30.8%) said they didn't know. The next largest category of responses (n=6, 23%) drew a one-to-one relationship between insulin and sugar control. At times the children could be very specific in their responses. One child made this clarification, "If there is not the right dose of insulin, your blood, well the sugar level in the blood, goes down or is too high. It goes to the brain or to other organs and makes them work too hard."

The next category of responses (n=4, 15.4%) reflected knowledge of the relationship between a diseased pancreas and insulin, with insulin taking over the role of a functioning pancreas. Three of the children responded by listing specific insulin types or specific aspects of insulin injection. Examples of responses in this category were, "the regular peaks at 2 hours and falls quickly, so NPH goes gradually up, peaks at 8 hours and falls gradually." and "When you put it in the shot, you roll it in your hands and then give it to me." The remainder of responses listed the specific
effects of insulin, such as, "It breaks down my food," and "It goes around in the body to help you feel good."

Blood or Urine Tests

Researchers have found that inaccurate knowledge of acetone, and its meaning when found in the urine checks, is cause for concern (Etzwiler and Sines 1962; Collier and Etzwiler 1971). In this study, only one child mentioned the word "acetone" in any of the interviews. This child had a reaction during the week and was describing it in detail. The child is an accomplished mimic and repeated that her mother had said, "You are spilling acetone like crazy!" It was my impression that this child knew that acetone in a urine check is not a good sign, but could not explain the causation or ramifications of the finding.

Although the children did not mention the word "acetone," several did describe an ideal color match in a urine check. The children may not have understood the physiology underlying these results, but they did have an empirical understanding of what is a proper urine check.
Table 2

"How does insulin work?"

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>8</td>
<td>30.8</td>
</tr>
<tr>
<td>Eats away/controls sugar</td>
<td>6</td>
<td>23.0</td>
</tr>
<tr>
<td>To replace pancreas</td>
<td>4</td>
<td>15.4</td>
</tr>
<tr>
<td>Explain insulin management</td>
<td>3</td>
<td>11.5</td>
</tr>
<tr>
<td>Helps me feel good</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td>Breaks down food</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Prevents reaction</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Opens cells, sugar gets in</td>
<td>1</td>
<td>3.8</td>
</tr>
</tbody>
</table>

----  ------

26   99.8
Diabetic children are no longer taught the use of urine tests as the primary check for sugar levels in the body. The improved technology of blood checks are preferred by health care professionals due to improved accuracy and speed of administration. Acetone is not a distinguishing factor in blood checks, and would not be a useful term for children using this type of check.

Although these children may not understand the intricate biology of their condition, they understood quite well the ramifications of a blood or urine test showing low or high blood sugar levels. One child explained how he wiped color off his test strips in order to make it appear that he had lower sugar levels and thereby assured himself a sugar treat. He also liked to sabotage his sibling’s blood test by passing on false information. He told his sibling that specific actions would make the blood test appear low when in reality, he thought these actions altered the blood test to read high, and would then cause problems such as reprimands from a parent or further restriction of sugar treats for his sibling.

MISCONCEPTIONS OF MANAGEMENT

The knowledge imparted in the professional sector of care is translated and adapted in the popular sector.
Since the majority of diabetic care takes place in the home, misunderstandings about proper diabetic management may not be discovered until situation arises which prompts reevaluation of daily management activities. Management procedures reinforced by parents set the stage for future perceptions on what constitutes "good" management. Etzwiler and Sines (1962) found that parents lacked the knowledge deemed necessary for successful management. Since continuing medical education takes place in the clinic and at home, this lack of knowledge could have serious consequences for future health.

One example was the information given as an anecdote by the father of one of the children interviewed. This father explained that close attention was paid to insulin injections in their home. He stated that, "Food and meal times may vary but shots are always on time." The child had also mentioned this during an interview. He said that during vacations they would get up in the morning at their usual time and have an insulin injection, then they would go back to bed.

This family felt that they were practicing responsible management. As outlined earlier, the amounts, types, and times of insulin injections should be coordinated as closely as possible with the schedule of meals and exercise. The health professional sets the parameters, but often the family will make minor
adjustments on a daily basis as the need arises. A delayed meal time could result in an imbalance episode. This family never altered the time of insulin injection even though their meal and exercise patterns shifted. Perhaps circumstances were favorable enough in this situation so as not to compromise the child's diabetic balance. However, this family's perception of what constituted good control and management provides the key to their possibly misguided actions.

Another example of a misconception of diabetic dietary restrictions was a child who had excluded all sweets from his diet. He was proud of himself and felt he was doing well, yet his blood sugars still ran high. It was discovered later that his idea of an after-school snack was eggs, sausages and toast. He then would eat a proper dinner, resulting in an excessive amount of food. Since both of his parents worked, this information was slow to come to light.
RESULTS - MANAGEMENT

The ultimate aim when dealing with diabetes is successful management of the condition. In essence, all management activities aim at producing acceptable blood sugar levels. By daily simulating the activity of a healthy pancreas, it is hoped that long term health will be improved and complications avoided. Two types of management are required in response to diabetes: daily management, and management of diabetic imbalance episodes (hyperglycemia or hypoglycemia). The following section will discuss these two types of management. In addition, general health strategies employed by these diabetic children will be examined.

DAILY MANAGEMENT

Daily management includes balancing the prime factors of insulin, diet, and exercise, and monitoring that balance by assessment of blood or urine tests. As presented in the previous chapter, while the children may not understand the underlying biological process necessitating management procedures, they are well aware of the importance of these daily tasks. Regulation of
diet and exercise, blood or urine checks, and insulin
injections not only create a schedule around which to
organize their day, but also provide a set of images
which structure their perceptions about the condition.
In particular, regulation of sugar and insulin injections
are conceptually linked to diabetes. As one child
stated, "when you think diabetes, you think shots."

**Blood and Urine Tests**

"I don't prefer blood tests, urine is easier. Blood
tests are more accurate, but it takes more time.
It's boring sitting there waiting for two minutes!"

---13 year old diabetic child who only
uses blood tests

Assuming responsibility for blood or urine testing
is the logical first step toward self care. It is a
concrete task, with immediate feedback. Neglecting to
perform a blood/urine test will put individuals at a
disadvantage, but will not immediately jeopardize their
health. Other management factors such as diet and
exercise are more abstract, and the results of non-
adherence may not occur until several hours later.

The children responded in the initial interview that
80.8% of them (n=21) conducted their own tests. This is
a much higher percentage than claimed responsibility in
insulin injection. This may reflect on the idea that
testing is a less traumatic entrance to self care, and is usually undertaken first (see Table 4 in the section on Insulin Injections). The only available test for many years was urine testing. Blood testing now is available and was used by many of the children. It is the test preferred by medical personnel due to its increased accuracy over the urine test.

Based on data gathered from the children at the time of the initial interview, 50% (n=13) of them did blood tests exclusively, 34.6% (n=9) conducted urine tests exclusively, and an additional 11.5% (n=3) used both blood and urine tests. This was a time of transition in the clinic, and patients gradually were being switched to blood testing. Data gathered from the final interview displayed a shift in testing methods. At the final interview, an additional 3 children had switched to blood testing (for a total of 16 or 61.5%), two more children were performing both types of test (n=5 19.2%), and only five children relied solely on urine tests (Table 3).

Although the children had firmly stated preferences for either blood (n=13, 50%) or urine tests (n=10, 38.5%), this did not always correlate with the type of test they utilized daily. Three children were not using their test of preference at the time of the initial interview (Table 3). Reasons given for preferring blood tests were convenience (n=5), the ease of process: "..can
do pricks (blood test) in the kitchen," "Sometimes I
don't have to go to the bathroom, but I can always
bleed!" (n=2), and avoiding an unpleasant social
situation: "...company comes and friends see you going to
the bathroom in a cup...with blood (tests) you can get it
over with" (n=2). The children also recognized increased
accuracy in blood testing and cited this as the reason
for their preference (n=2). When asked why they
preferred blood testing, two children simply stated, "I
just do." One child believed she spoke for the entire
diabetes population when she stated that, "most kids who
are diabetic like blood tests."

Although children may recognize that blood tests are
medically more accurate and socially less awkward, some
still prefer to use urine tests. The pain and aversion
associated with pricking a finger (n=5), a general
dislike of blood (n=2), and ease of process (n=1) were
the reasons given for their preference. One child did
not state a reason for her preference.

The most interesting responses were from the
children who used both types of tests, according to their
needs, or as a compromise (n=3). One boy said he did a
urine check initially in the morning when, "I'm too tired
to do the other (blood)." He then performed blood checks
during the day. The other two children did not prefer
blood tests but recognized the superior accuracy of this
method. One child said "when I'm sick I do blood...it gives a better reading," indicating the need for closer vigilance to sugar levels when illness occurs. The second child stated that "...urine doesn't hurt...blood is better but everybody prefers things that don't hurt." For now, this compromise seems acceptable to the children and their health care professionals. For children who have to face several needles a day, additional pain in the form of blood testing could lead to lower adherence levels.

The medical technology of blood or urine tests provides an objective measures to support subjective feelings of illness. The children used these objective measures further to substantiate their perceptions of health or illness. One child explained that he felt his best when "I am right on the dot, 1% [blood sugar]."

Another child used blood sugar levels as a gauge for physical and mental health, "Physically [I feel best] when I'm not on the high end. The middle half is good. At five percent I feel grouchy and when I am negative I just don't feel good. I'm shakey and don't know who I am."
Table 3

**Type of Test Conducted to Determine Glucose Levels**

<table>
<thead>
<tr>
<th>Type of Test</th>
<th>Initial Interview</th>
<th>Final Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Total %</td>
</tr>
<tr>
<td>Blood</td>
<td>13</td>
<td>50.0% *</td>
</tr>
<tr>
<td>Urine</td>
<td>10</td>
<td>38.5% #</td>
</tr>
<tr>
<td>Blood &amp; Urine</td>
<td>3</td>
<td>11.5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>26</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

This table reflects the type of test actually used, not the children’s preferences.

* Two children in this category preferred a urine test
# One child in this category preferred a blood test
The children were asked how many times a day blood/urine tests were conducted. The ideal would be multiple times a day. Doctors often suggest four times a day, before each meal and before bedtime. Only four children (15.4%) reported conducting all four tests. Slightly more than half of the children, (n=14, 53.8%), reported conducting three tests daily. One child claimed to conduct no consistent testing, with the remaining responses being two tests daily (n=4, 15.4%), and 1 test daily (n=3, 11.5%).

**Insulin Injections**

"The insulin shot is your pancreas... I look at it like your pancreas is your arm and legs. That's where I get my shots."

---12 year old diabetic child

The major physiological malfunction in diabetes is the inability to produce insulin. Daily insulin injections are used to compensate for this deficiency with the goal of producing near normal blood glucose levels. Maintenance of insulin balance is not only necessary for biological functioning on a daily basis, but it is thought that this may lessen the occurrence and severity of future complications (Cahill and McDevitt 1981).
A medical professional determines the timing of injections and the type of insulin best suited for the child's needs. These injections are given at home. This means that information formulated in the professional sector is translated, evaluated and executed in the popular sector. The literature suggests various ages when insulin injections should become the prime responsibility of the child, with recommendations ranging from 8 to 10 years old (Kennedy 1955) to not before 12 years of age (Partridge et al. 1972). Etwiler and Sines suggest self-care should not be assumed "... until the child can comprehend the important fundamentals of their illness and its management" (1962:307). Injections are the hallmark of self care for the children, and often signals additional independence and increased mobility.

Of the 26 children in this study, 15 (57.7%) claimed to be self-injectors. Most of these children (n=13) ranged from 9 to 12 years old. In addition, two 8 year olds claimed to have prime responsibility, but needed help when rotation of injection sites necessitated shots in hard to reach areas, such as an arm or the "behind." Mothers were the next largest category of individuals responsible for injections (n=8, 30.8%). Both parents were listed in two cases, indicating families in which fathers also take responsibility for daily diabetic caregiving tasks. Since injections are an important
marker of self care, the possibility exists that these children offered what they thought was the socially desirable response and exaggerated their involvement in self-injection. On the other hand, two children (ages 7 and 11) readily admitted they did not like to self-inject, so others did it for them (see Table 4).

Proper insulin administration includes sterilization of implements, drawing up of the correct types of insulin into the syringe, and actual injection into the body. It could not be discerned from these interviews if the same person was responsible for all of these actions. The children simply were asked who gave them their insulin shots. The children also were consistent concerning self-injection between the initial and final interviews. Only one additional child claimed to be a self-injector at the final interview. This child was extremely shy and many of her responses were missing in the initial interview. Hence there was essentially no change in this response category over the 3 to 8 month time span bridging the initial and final interviews.

Each child also reported the time of day injections were administered. Two injections daily were received by 65.4% (n=17) of the children. The remaining 34.6% (n=9) children received one injection daily. Although medical charts were not complete enough to cross-check, these responses are within the range of prescribed regimes.
Stated times of injection, usually in the morning and before the evening meal, also were appropriate.

Sanctioned injections of any kind are most often associated with the professional sector of health care. In the case of diabetes, the popular sector—most often the child and their family—assume responsibility for this task. Giving or receiving injections outside the professional sector in our society are generally stigmatized because of their association with drug abuse, illegal activities, and risk factors for transmission of disease. Diabetic children must face daily not only the pain of injections but also the stigmatization of an act that is often associated with deviance. The transformation of this behavior into an accepted part of a life-long routine requires that the diabetic child not only assume responsibility for this task, but also that the child suspend the usually held social definitions of appropriate behavior.
Table 4

Who Administers Insulin Injections and Conducts Tests?

<table>
<thead>
<tr>
<th>Person</th>
<th>Injections</th>
<th></th>
<th>Tests</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Total %</td>
<td>N</td>
<td>Total %</td>
</tr>
<tr>
<td>Child</td>
<td>15</td>
<td>57.7</td>
<td>21</td>
<td>80.6</td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
<td>30.8</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td>Parents</td>
<td>2</td>
<td>7.7</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>3.8</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Everybody</td>
<td>---</td>
<td>---</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Missing</td>
<td>---</td>
<td>---</td>
<td>1</td>
<td>3.8</td>
</tr>
</tbody>
</table>

        |        |          |        |          |
| 26      | 100.0  | 26      | 99.9   |
Diet

"It [diabetes] keeps you from eating stuff at parties. When kids ask me to take something I can’t have, I say I don’t like it."

---11 year old diabetic child

Diet is an important factor in the overall management of diabetes. Not only must specific foods be avoided, but definite parameters exist as to the amount of each food group that should be eaten and the times during the day when major meals should commence. As one child stated, "... you must eat regular meals, no sweets - it shoots blood sugar up high... You have to eat all of your meals. It doesn’t include spinach, thank God!"

The children spoke about the regulation of food throughout the interview schedule, even when the questions were not specifically aimed at eliciting this information.

Children under 13 years of age do not shop for food, nor do they regularly prepare meals for the family; thus, meals in the home are regulated by a parent. This regulation of meals has an impact on the entire family. When asked if their family did anything differently now that diabetes was a factor in their lives, five children (19.2%) stated that a change in diet had occurred in the family. Responses such as, "They eat differently now, they eat what I eat," "My mother used to make a lot of
cakes. Now she makes them half with icing and half without," and "[we] eat earlier and better" are examples of these changes in family diets. Many of the children also mentioned specific meal times. Not only were food choices being altered, but eating schedules became regulated.

The avoidance of sugar often was mentioned, and is the area in which the children have the most obvious control over their diet. A child told me weekly that she was trying not to "eat so much and trying not to eat sugar." This was an important issue to her because her physician had just deleted a second afternoon insulin injection from her management routine and diet had to be adjusted accordingly. This child was emphatic as she stated, "I do not want to go on an afternoon shot. I got off it and I do not want to go back on it - I hate it!"

The children seemed to take responsibility for aspects of their diet. One child explained that his blood sugar was high that day because he "cheated on his diet" at a school carnival. Another incident was more severe. This child was vomiting and was experiencing polyuria. His mother told him he deserved to be sick since he had not been acting right and eating a lot of junk. His father told him to run around to lower his blood sugar, but it really didn't help this time. When asked if this would happen again, this child responded
that it probably would since he would "give in to
temptation."

The weekly phone interviews overlapped with
Halloween for many of the children. Some interesting
coping responses emerged to deal with this candy-oriented
event. Three strategies were repeated when speaking with
the children. First, parents held a Halloween party in
their home, which allowed for regulation of food types
and amounts. The parties could also be activity-oriented
as opposed to food-oriented. Second, the children did go
trick-or-treating but gave the candy to their parents to
distribute in small doses or simply throw away. The
third strategy was related by one child who said that he
went out and collected candy, but when he came home his
parents went with him to buy appropriate food and toys to
replace the candy.

Avoiding parties due to limited food choices was not
reported to be a major issue by these children. This
could be due to hosting parents being made aware of these
children’s special needs, healthy substitutes being
offered in place of "party foods," or the ability of the
diabetic children to manage their diet in different
social situations.
EPISODE MANAGEMENT

The translation of signs of discomfort into symptoms of ill health is the first stage of entering the health seeking process (Chrisman 1977). The recognition of symptoms indicating imbalance must be made. Diabetic children must maintain a constant vigilance in regards to symptom awareness, as opposed to healthy children who may not have the continuous and urgent need to interpret bodily sensations. After recognition of a state of ill health, a decision must be made regarding appropriate action. Diabetic children must discern specific symptoms which indicate hyperglycemia or hypoglycemia. One child stated that, for him, headaches signalled the onset of diabetic imbalance. He further elaborated that this meant that he was high (hyperglycemic), plus he would get hot, sticky, and irritated. Low blood sugar (hypoglycemia) made him tired, dizzy and dreamy.

Alternately, children must decide if the symptom indicates a general state of ill health, and is non-specific to diabetes. Even if the symptoms are categorized as non-diabetic in nature, action often is required to assure diabetic balance with the onset of illness. Illnesses associated with anorexia or vomiting require particular attention to insulin levels (Weil
1977) since the balance of food and insulin is difficult to maintain in these instances.

During weekly interviews, the children related their illness episodes, if any, and their responses to each episode. They were told not to limit their information to diabetic episodes. The symptoms indicated by the children as identifying illness and the action taken to alleviate those symptoms are illustrated in Figure I.

Three hundred thirty three weekly interviews were collected. The 26 children experienced 46 diabetic episodes and 15 non-diabetic illness episodes. For each of these illness episodes, symptoms (indicators of ill health) and responses were elicited from the child. These symptoms and responses were grouped after data collection into the categories displayed in Figure I.
Figure 1: Simultaneous Plot of Symptoms and Responses

- Mental Confusion
- Insulin Management
- Seek Medical Professional
- Alter Behavior

Symbols:
- X = symptom
- ■ = response

- Weakness/Pain
- Headache
- Cold
- Rest
The simultaneous plot of symptoms and responses in Figure I was created using multi-dimensional scaling. This procedure, also known as smallest space analysis, allows the creation of a matrix of similar pairs (Mitchell 1980). In this plot, symptoms are represented by "x" and responses are represented by squares. The spatial proximity of specific responses with symptoms is an indicator of the magnitude of their association. This procedure allows visualization of relationships in the data set that might otherwise be difficult to discern. Further elaboration of the data entered and the process used to create Figure I is contained in Appendix II.

Clusters of symptoms and responses emerge. Elements closest to each other result from the most frequently paired items in the data pool. With the exception of the symptom of mood alteration, two possible responses occur in each symptom/response cluster. One is within the realm of the child, and the other might necessitate adult intervention. For example, when symptoms indicated a diabetic reaction, the two most frequent responses involved altering behavior or seeking professional medical care. Altering behavior (slowing down, being more vigilant) is an action any child can take unaided and without permission. However, in most circumstances an adult must intercede on the child's behalf to obtain professional medical help.
Consumption of food or drink was most often utilized as a response to the symptoms of weakness/pain, headaches, and mental confusion. The other response to these same symptoms was insulin management. In this case, food provides a means of response well within a child’s capacity. It is an action that can be undertaken independently, unlike increasing or decreasing units of injected insulin. Although, as discussed earlier, many of these children were self-injectors, an adjustment in the insulin levels usually is accompanied by a consultation with a parent or medical professional.

Healthy children also use regulation of food patterns as a response to illness episodes. A study by Korbin and Zahorik (1985) indicated that not only did children list regulation of food or drink as a remedy for illness, they particularized this response pattern more often for stomach aches over colds or headaches. Thus, not only did children from a healthy population and in this diabetic population recognize the role of consumption as a remedy, it was not used randomly across ailments.

Although the children in the Korbin and Zahorik study never listed consumption/exclusion of food or liquid as a remedy for headaches, it must be remembered that theirs was a presumed healthy population. Headaches in diabetic children are usually caused by a hypoglycemic
state, and consumption of food or drink is the recommended action.

A report of one diabetic incident in particular serves as a good example of the process and detail of a child’s experience with imbalance episodes. This child was swimming, a daily summer activity, and began to feel dizzy. When asked in the interview, "What was the first thing that you did about this feeling?," her emphatic response was, "I got out of the water. I didn’t want to go into insulin shock in the water!" She then described "tripping" out of the pool; a feeling of being uncoordinated which was used as an indicator of imbalance in other children's reports. She told her mother, who gave her a sucker, which she said "didn’t work fast enough." At this point, the child told her mother that she felt like she was going into insulin shock. Her mother tried to give her instant glucose. The child related that "it tasted yucky so I wouldn’t eat it. I told her it tasted bad, I talk snotty when I’m in insulin shock." Her mother then carried her to a friend’s house and gave her sugar and tang. As the child began to feel better, she could "see better and was not so dizzy." They then returned to the pool and her mother "got the man to let us in the snack shop and give me candy and coke."
Figure I further indicates that cold symptoms are spatially removed from symptoms which have a diabetic component. Rest and medications were used in response to these cold symptoms. Medicines in particular were associated only with cold symptoms. Not only is insulin not described as a medicine, but medications have little to do with the diabetic illness experience. Even headaches, which are often medicated with aspirin (or a comparable drug) in the general population, are not designated outside the diabetic symptom clusters. Thus it appears the children already have developed specific, well defined responses to symptom manifestation. This separation of diabetes and other illness states by children may be expanded into the professional sector of care. A seven year old diabetic child offered this explanation of her relationships with her physicians: "Doctor X didn't know anything about diabetes. We had to call in another doctor. We'll see Dr. X sometimes, but he is just a "catch-a-cold" doctor now."

An additional element to these response patterns was the incorporation of blood or urine checks. These tests were utilized in two different ways - to verify a biological state that could produce symptoms of imbalance or, in the case of non-diabetic illness episodes, to monitor changes in diabetic balance while experiencing illness. As one child explained this phenomenon, "When I
am sick, I am high [blood sugar] a lot." Thus, as presented earlier, the children have an objective measure by which to measure their subjective health and illness states.

HEALTH MANAGEMENT

"Health is considered a reflection of an individual's ability to adapt to the environment by biological or behavioral means" (Moore et al. 1980:10). Health as opposed to illness is not often looked at; it is assumed to be the status quo. However, individuals do take action consciously, and unconsciously, to assure health. Health often is more difficult to define. It often is viewed as the absence of disease or illness symptoms as opposed to an entity unto itself. For people living with a chronic illness, health is not a given. Health is a perceived state to work towards - a process needing constant vigilance.

In order to approach the weekly interview in a positive light, the initial question was, "What do you do to stay healthy?" This enabled the children to list aspects of health maintenance without restricting their answers to the realm of diabetes care. Not a single child said that they did nothing to obtain health. It
was not taken for granted that health just occurred. Everyone took some action to ensure good health.

Twenty-five children articulated five categories of responses (Table 5). The largest category of response (n=22, 44.9%) was food vigilance. Exercise vigilance made up the next largest category of response (n=11, 22.4%). This included both making sure that a form of exercise was included daily, and monitoring exercise and play so that too much would not topple the insulin balance. The third largest response pertained to insulin injections. The children offered this response 20.4% of the time (n=10). Thus the three major factors involved in diabetic management made up the largest categories of response.

The remaining responses included performing blood or urine checks (n=4, 8.2%), and being vigilant in the daily schedule of events (n=2, 4.1%). These responses demonstrate that the children are aware of the factors require attention to avoid diabetic imbalance episodes, and include these factors in their definition of health.
### Table 5

**Health Management Strategies**

<table>
<thead>
<tr>
<th>STRATEGY</th>
<th>N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>(responses)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food vigilance, avoid sugar</td>
<td>22</td>
<td>44.9</td>
</tr>
<tr>
<td>Exercise vigilance</td>
<td>11</td>
<td>22.4</td>
</tr>
<tr>
<td>Insulin injections</td>
<td>10</td>
<td>20.4</td>
</tr>
<tr>
<td>Blood/urine tests</td>
<td>4</td>
<td>8.2</td>
</tr>
<tr>
<td>Schedule vigilance</td>
<td>2</td>
<td>4.1</td>
</tr>
</tbody>
</table>

49 100.0
Some of these responses may not be particular to children experiencing a chronic illness. In a study with urban 5th and 6th graders, Korbin and Zahorik (1985) found that their population listed many health maintenance strategies. Indeed, dietary practices and exercise were two of the top three strategies listed. Again, it is noteworthy that the strategies articulated most often are those within the control of the children.

The children were influenced by the medical and social implications of their management procedures. They described decision processes to utilize blood or urine tests, vigilance in food intake, and a constant need to adhere to a schedule of management tasks, all of which have recognized social implications. The next section of results addresses descriptions of the children’s perceptions of the social stresses and stigmas concomitant with their diabetic condition.

Overall, the children displayed an orientation toward health maintenance as opposed to illness avoidance. The two most frequent responses given as health management strategies -- food vigilance and exercise vigilance -- are desirable activities, promoted in the medical and popular literature as actions that should be taken by all individuals in order to maintain health. Although children with diabetes must achieve a careful balance of these actions (plus insulin
injections), they also look upon these activities as a means of obtaining overall good health, not just diabetic balance. This health perspective, centered on diabetic management, provides the key to these children's abilities to transform this threatening disease far beyond the more benign orientation of illness prevention to the very positive perspective of health maintenance.
RESULTS-LIMITATIONS AND COPING

A child with diabetes must learn to cope with diabetes as a medical condition and maintain homeostasis by means of the management strategies presented in the previous sections. In addition to maintaining biomedical integrity - coping with the disease aspects of their condition - these children must develop strategies to mediate the illness components of diabetes. The very process by which the disease of diabetes is transformed into illness, "the psychosocial experience and meaning of the perceived disease" (Kleinman 1980:72), is part of the coping process. In this sense, coping mechanisms are those intentional cognitive or behavioral efforts made in an attempt to mediate stress. Coping involves the active development of strategies where there is no routine action available (Curry and Russ 1985). These active strategies were elicited from these children with diabetes.
PERCEIVED LIMITATIONS

"Is there anything you don't like about diabetes, anything that frightens you?"
"No, not really. I wouldn't mind except for the sugar. If I couldn't breathe, then I would mind!"

--- eight year old diabetic child

The children were asked if there was anything they did not like about diabetes. Their responses are listed in Table 6. The first column lists the number of times a particular response was offered by the 26 children. The second column is the calculated percentage of children that offered a response. The children were not limited in the number of responses they could offer to this question. Therefore, percentages do not equal 100% (Table 6).

Although six children (23.1%) stated that there was nothing in particular about diabetes that they disliked or that frightened them, displeasure with the daily management procedures of injections, disallowed foods, and blood/urine tests accounted for the largest portion of the children's responses. One child described his dislike of these aspects by reeling off his response in a well known litany, "[I don't like] shots and getting tested every morning... eating breakfast at 8:00 instead of 9:00, eating snacks at 10:00, lunch two hours later, snacks again two hours later, dinner, snacks..." This
dislike for daily management procedures also has been recorded in other studies with diabetic children (Sperlich 1982).

The impact of necessary management procedures is further reflected in the responses highlighting time management. The necessity to be at home for injections or interrupting play for meals and tests was listed by four of the children (15.4%). Examples of the responses in this category include: "It takes time away from friends. I have to come inside and do everything." and "Sometimes it is really the pits. It takes up your time."

Future diabetic complications such as ruined kidneys and blindness was a concern for three children (11.5%). Two children (7.7%) had very philosophical outlooks and voiced, "Nothing frightens me. I can live with it but I don't like it. I'd like to find a cure some day." and "I had a dream last night that no one had invented insulin. That could really be serious. People died from diabetes back then. It's still serious now."
Table 6

"Is there anything you don't like about diabetes?"
(initial interview)

<table>
<thead>
<tr>
<th></th>
<th>Number of responses</th>
<th>% of children offering a response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Must have injections</td>
<td>9</td>
<td>34.6</td>
</tr>
<tr>
<td>Disallowed foods/candy</td>
<td>8</td>
<td>30.7</td>
</tr>
<tr>
<td>Nothing</td>
<td>6</td>
<td>23.1</td>
</tr>
<tr>
<td>Time Management</td>
<td>4</td>
<td>15.4</td>
</tr>
<tr>
<td>Blood/Urine tests</td>
<td>3</td>
<td>11.5</td>
</tr>
<tr>
<td>Future Diabetic Complicats</td>
<td>3</td>
<td>11.5</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td>Everything</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>3.8</td>
</tr>
</tbody>
</table>

* The children were not limited in the number of responses they could offer to this question. Therefore, percentages do not equal 100%.
The previous section focused on the aspects of diabetes that the children found distasteful or frightening. The children also were asked to list any limitations that the diabetic condition created for them. These responses were used to created a spatial diagram, using multi-dimensional scaling techniques. This procedure, also known as smallest space analysis, allows the creation of visual relationships between the data (Mitchell 1980). Responses which were most often elicited together appear in closest proximity to each other in Figure II.

The most obvious grouping in the figure concerns food restriction. The children discussed necessary rules about food consumption in the diabetic regime. The cluster towards the center of the figure includes three different aspects of diet. Explanation of the elements of this cluster includes: "disallowed foods," "no parties," and "must snack." "Disallowed foods" refers to specific foods which are restricted from the diabetic diet, most often those with a high sugar content. Food limitations, which can be a trial for both the children and their parents, was a focus throughout the interview process. A mother of diabetic siblings told me that "all those two kids think about is food." She also said that she often found candy wrappers in the bathroom, where she suspected the children hid and ate restricted foods.
Figure II

TWO DIMENSIONAL REPRESENTATION OF PERCEIVED LIMITATIONS OF DIABETES

- Nothing

- Disallowed food
- No parties
- Must snack

- School performance
- Interrupt play
- Other restrictions

- Insulin injection
- No sleep
- Over injection
"No parties" again refers to food restrictions due to the fare most often offered at parties. The children employed two coping strategies in this area. Either they did not attend parties, or they planned alternative consumption or insulin injection patterns before parties. As one child stated, "When I go to parties I either take my own food or I just don’t eat." This example further demonstrates the manner in which diabetic management becomes a social concern.

The third element included in this cluster, "must snack," refers to a need for regulated eating times. Some diabetic children need to take a mid-morning or afternoon snack. On school days, the need to eat in front of other children who do not partake further singles out these children as different. A child commented, "If I need to eat (in school) it bothers me. People ask questions." Another child said the first day of school always makes her sad, "I get embarrassed on the first day of school. I have to eat a snack and people look at me like "Are you sick?" and then I have to pass up other [student or school-provided] snacks. I say, "Just skip me." then they say, "Why, don't you like it?" and I say, "Yes, but just skip me."

A need to maintain eating schedules also impacts on family events. During a conversation about religion and family, one child related this about her family, "Well,
we are and we aren't [religious]. We usually go to
church on Sunday, but we don't stay for the whole thing
from 11:00 to 1:00 because I need lunch."

The second cluster of "no sleep-over" and "insulin
injections" again evince how a management procedure makes
a direct impact on the social arena of childhood. Since
insulin injections are administered at specific times
(the morning always being one of those times), the
children were not allowed to sleep-over at friends' homes
until they had sole responsibility for insulin
injections. Even if the children did participate in
sleep-overs, management tasks and the necessary
paraphernalia cannot be ignored. As one child said, "I
have to take syringes to kids' houses when I sleep-over."
Other factors which were unspoken but might be of concern
include providing dietary needs and medical care in case
of an imbalance episode while visiting at friends' homes.

The third cluster is in the upper right corner of
the figure. This cluster includes "interrupt play" and
"other restrictions." These factors refer to the
schedule vigilance that must be heeded to maintain
diabetic balance. The children related that they must
stop playing and go inside to receive a meal or injection
on time. "Other restrictions" also were quality and
time-oriented. Children complained that they could not
play very hard or for long periods of time, "When I play,
like when I play tennis, I can only play for about an hour before I get tired. When I swim I get really tired." One child shared her woes, "I'd like to be able to be more active and not have to watch everything so closely." These responses again highlight that, although diabetes may not be a visible illness, behaviors that are necessary to maintain management schedules indicate that the child is different. Even if other children do not notice these behavioral differences, the diabetic child does and they impact socially and physically on their world.

The impact of diabetes on school performance also was a concern for these children. One child explained that it "interferes with work because we have tests and I get nervous and that brings down the sugar." A headache is the result of the changing diabetic states, and this further affects his school work. Another child restated this phenomenon in response to a separate question, "If I am really high [blood sugar], I won't do as well on a test.... It slows up your brain and you can't think as well." Diabetic children must go beyond learning how to maintain physiological balance to developing skills that can mediate the effects of social and academic demands on their physical and mental states.

A mother with diabetic children related an example of the possible consequences of imbalance episodes in the
classroom, which is often a structured setting with enforced regulations. Her son was experiencing mild polyuria, a symptom of diabetic imbalance. He had wet his pants several times because he was not allowed to visit the bathroom repeatedly. After this experience, she enrolled her children in a private school even though it was an hour away from their home.

PERCEIVED STRESSES

Stressful life events have been measured most often in the literature by means of the Social Readjustment Rating Scale, developed by Holmes and Rahe (1967). This scale has been used to rate the effect of 43 situational and developmental stresses on adults. The scale was modified, for use with children, by Coddington (1972). Coddington designed lists of stress items for high school, junior high, elementary, and preschool children. These stresses were given a rank order based on the assessments of teachers, mental health workers, and pediatricians. The total amount of psychosocial readjustment a child undergoes during a specific period of time was calculated from these data.

Kosub and Kosub (1982) utilized Coddington's scale in their investigation of diabetic children's perceptions of stress. Children in the Kosub study were asked to
list stressful items independently and also were asked to rate a modified Coddington's list of stresses. There was a low correlation between the children's generated lists and Coddington's rankings. This is an indication that professionals' rankings of stresses does not necessarily predict children's perceived stress experiences.

As a comparison, the children participating in this research first were asked to list the top three stresses in their lives. Diabetes was not mentioned specifically by the interviewers at this time, since one point of interest was the percentage of time the children noted diabetes as a general stress in their life. After they completed this list, they were asked to list the top three stresses specifically having to do with diabetes. If the children did not understand the word "stress," the definition offered them was "anything that caused them to be extremely sad or happy, or something that created pressure, problems or worry." All stresses listed are displayed in Table 7.
Table 7 - Generated Lists of Stresses

<table>
<thead>
<tr>
<th>STRESS</th>
<th>GENERAL*</th>
<th></th>
<th>DIABETIC*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Total %</td>
<td>N</td>
<td>Total %</td>
</tr>
<tr>
<td>School</td>
<td>12</td>
<td>20.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family concerns</td>
<td>12</td>
<td>20.3%</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Misc., sad</td>
<td>6</td>
<td>10.2%</td>
<td>2</td>
<td>3.6%</td>
</tr>
<tr>
<td>Insulin, shot</td>
<td>4</td>
<td>6.8%</td>
<td>10</td>
<td>19.2%</td>
</tr>
<tr>
<td>No Sugar/Parties</td>
<td>4</td>
<td>6.8%</td>
<td>8</td>
<td>15.4%</td>
</tr>
<tr>
<td>Friends, happy</td>
<td>3</td>
<td>5.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vacation, outings</td>
<td>3</td>
<td>5.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misc., happy</td>
<td>3</td>
<td>5.1%</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Harm, hurt to self</td>
<td>3</td>
<td>5.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
<td>3.4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends, social pressure</td>
<td>2</td>
<td>3.4%</td>
<td>3</td>
<td>5.8%</td>
</tr>
<tr>
<td>Allowed restricted food</td>
<td>1</td>
<td>1.7%</td>
<td>3</td>
<td>5.8%</td>
</tr>
<tr>
<td>Diabetic camp</td>
<td>1</td>
<td>1.7%</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Blood/Urine tests</td>
<td>1</td>
<td>1.7%</td>
<td>9</td>
<td>17.3%</td>
</tr>
<tr>
<td>Diabetic reaction</td>
<td>1</td>
<td>1.7%</td>
<td>7</td>
<td>13.5%</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>1</td>
<td>1.7%</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Diabetic complications</td>
<td></td>
<td></td>
<td>2</td>
<td>3.8%</td>
</tr>
<tr>
<td>Taking care of self</td>
<td></td>
<td></td>
<td>2</td>
<td>3.8%</td>
</tr>
<tr>
<td>Maintain diet</td>
<td></td>
<td></td>
<td>2</td>
<td>3.8%</td>
</tr>
<tr>
<td>Total</td>
<td>59</td>
<td>100.1%</td>
<td>52</td>
<td>99.9%</td>
</tr>
</tbody>
</table>

* All children did not list three stresses in both categories. The perceptions of some children may be represented more than others.
The top three stresses are different for the two lists generated from the children's responses. No diabetic item ranked in the top three stresses on the general list. The general list ranked school ("tests in school," "being in school all day"), family concerns ("worry about mom and dad and accidents in snow and rain," "mom and dad got divorced," "when I get punished") and miscellaneous sad events ("when somebody bothers me," "when someone beats me up," "when someone falls") as the most stressful. The children in the Kosub study listed the death of a grandparent, parent, or sibling, and parents fighting as their top stresses.

The top three items on the diabetic list included having insulin shots, conducting blood/urine tests, and avoiding sugar. If categories from the diabetic stress charts of these children are combined, 13 responses, the largest category of diabetic stress, are associated specifically with food choices: no sugar/parties, allowed restricted food, and maintain diet. Diabetic management strategies are very dependent upon the individual's food exclusions and intake. Dietary beliefs and practices are one of the most difficult cultural patterns to change. In addition to trying to modify ingrained dietary habits and preferences, a diabetic diet may mean adjusting social activities associated with
hospitality and special events (Blevins 1979), and "rites of passage" such as sleep-overs, parties, and the first beer.

The interrelationships between social events, diet, and the diabetic state were illustrated by one child's response when she was asked if her family was religious. She responded that her father was Catholic and she and her mother were Jehovah Witnesses. Jehovah Witnesses claim that biblical teaching does not support the celebration of Christmas, which they believe has its origins in a pagan holiday, nor the celebration of anyone else's birthday (Beckford 1975). This child's family did not celebrate Halloween, Thanksgiving or birthdays. During a weekly call a surprise party was being given for the child and her sister. She explained it was "just because," not a birthday or holiday. These actions reflected religious beliefs but also allowed control over special events, which often involve forbidden foods.

The children recognize and articulate that they are experiencing stress in conjunction with their diabetic state. The fact that these stresses appear on their lists, but are not the overwhelming concern for these 7 to 12 year olds, leads to several possible conclusions. Perhaps these children have developed coping and management styles which allow them to minimize the stresses of diabetes. Diabetes also may act as a
confounding variable by contributing to the stresses experienced in school and family life. Although these children do not immediately rank diabetic concerns in their general stress lists, factors associated with diabetes do appear throughout this general list. Diabetic stresses are experienced in many spheres of these children's lives.

THE SOCIAL SELF

"Only my mean friends tease me. They say, "You can't do other stuff we can." I say, "Name one!".

---11 year old diabetic child

The majority of children interviewed for this study (n=22, 84.6%) said that they did not feel different from other children. They did recognize necessary behavioral differences, such as adhering to dietary patterns and management schedules. The fact that diabetes is a condition with set management patterns lessened the perceived severity of the condition. When asked, "Is this [diabetes] a bad condition?", 16 (61.5%) of the children said "no" and one stated that it was "manageable." When asked if diabetes was worse than a cold and/or chicken pox, ten (38.5%) of the children said it was not worse than a cold. Of the twenty children who had experienced chicken pox, 11 (55.0%) stated it was not worse than chicken pox.
When asked about peer reaction to the diabetic condition, 17 (65.4%) of the 26 children stated that their friends did nothing special, or just treated them normally. Five of the children (19.2%) stated that their friends were supportive of matters related to diabetes, and would give them sugarless gum or walk them home when they needed something to eat. Only 2 children (7.7%) reported that some of their peer group had responded negatively to their diabetes, teasing them or shunning them as playmates. Responses from two of the children were not gathered for this question.

The majority of children (n=21, 80.8%) stipulated that no one could discern their diabetic condition unless they were told specifically. One child told a few of his friend in case he got sick, so they could help. Another child complained that he had never told his friends that he had diabetes but his sister (also a diabetic) did. He went on to explain, "That's why I'm losing all my friends on the street. They never come over anymore, I have to go over there." He then elaborated, "The only other person I know who knows about diabetes is my coach." Another child stated that her physical attributes gave her away. She said, "Yes, [people can tell that I have this condition] I'm the only one in the class that's skinny. I feel sad that they know, I don't want them to. One time a friend shouted it out and everyone heard and
the friend laughed. It hurt my feelings. It happened in nursery school. I didn’t tell anyone then because I was too scared."

Of the 14 (53.8%) children who had attended diabetic camp, 4 (28.6%) stated that the experience helped them by exposing them to other diabetic kids. When asked what they enjoyed most about the camp experience, 10 (71.4%) children listed being involved with other children who had diabetes. This enjoyment was not only due to knowing someone like themselves, but to having common experiences by being on the same schedule and eating the same foods. The experience of relating to a group who took diabetes for granted (Goffman 1963), and the normalization of management tasks and imbalance episodes was truly appreciated by children attending camp.

The children also were asked what their brothers and sisters thought about their diabetic condition. The majority (n=15, 57.7%) said that they did nothing or treated them normally, "They don’t make fun of me. They think I’m a regular brother." and "They seem not to care. They treat me like a regular person." One child had no problems with her sister, but her cousin was not so understanding, "My sister doesn’t even make fun of it. She doesn’t care and thinks of me as a normal sister. But my cousin, bugs me. She thinks it’s catchy. She
won't take a lick off my sucker or anything. But I don't really care about her."

Four of the children (15.4%) spoke of their siblings as having an active role in diabetic management by practicing vigilance, "They're great. They help me out a lot. They tell me to eat all the stuff at dinner. Sometimes I don't want to but they tell me to eat it and help me if I need it." and "She [her sister] is worse than my mother. If there is the least bit of sugar in something, I can't have it." Two children (7.7%) stated that their siblings, who also were diabetic, had a negative reaction to their own diabetes, "He doesn't like it but it doesn't bother him." and "He doesn't think it is very good because he wants to eat Pac Man cereal." Only one child claimed to be teased by a sibling, while another said that a sister was "glad because she can eat up all the ice cream and candy." Two children didn't know what their siblings thought and one response was missing.

The children were asked what was the best part about being a diabetic. Eight children (30.8%) felt that they were healthier as a result of daily management of diabetes. Responses such as, "You know you will be healthy when you grow up - you don't eat all that sugar that regular people eat. You might live longer than other people."; "You eat healthier things than other
people - you look better, you don't have too many pimples." and "In a way you are healthier. You don't eat all that sugar and you have to exercise." seems to reflect a health belief that vigilance in diet and exercise and the avoidance of sugar balance the possible deleterious effects of diabetes. Four children also listed a reduction in cavities in their teeth as a benefit of diabetes. Morbidity associated with a poor diet and lack of exercise is a leading cause of death in the United States, and public education efforts on healthy life-styles is in the media. Perhaps it is not surprising that these children view enforced diabetes management as a path towards health.

Seven of the children, (26.9%) stated that there was nothing positive about the diabetic condition. Their responses were short and to the point, "There is not really anything."; "Nothing is really good."; and "I don't think there is one."

Three children (11.5%) listed the manageability of the condition and lack of distinction from their peers as a positive aspect. As one child stated, "It is better than other diseases. I don't really notice it. I just have to take shots and take care of myself." Another child responded, "I get to do the same things other people do." Other advantages of the diabetic condition included additional attention from parents (n=2), eating
at school (n=2), attending camp (n=1), and avoiding military service (n=1). Two children stated, "I don't know" in response to the question.

The children listed a variety of occupations in their future plans. The children aspired to be scientists, engineers, teachers, doctors, stuntmen and concert pianists. One child elaborated on her plans for the future, "I always wanted to be a nurse. Lots of kids said I would be good since I know about shots, tests and being healthy." Another stated that she "might be a dietitian and go into research. I heard about a woman who wanted to be a dietitian who also had diabetes."
CHAPTER V

CONCLUSIONS

The purpose of this study was to gain an understanding of how children with juvenile diabetes explain and manage their condition. A second goal was to explore these children's reported health maintenance strategies and illness behaviors. A third goal was to demonstrate that children are meaningful informants on health and illness issues and lend support to the benefits of eliciting their beliefs and analyzing their behaviors.

SUMMARY AND DISCUSSION

Two themes must be emphasized before expanding specific points from the results. These two images unify the areas of diabetic knowledge, health and illness behaviors, and coping strategies. The first is the concept of constant vigilance to management which pervades every aspect of the diabetic experience. The second is the overwhelming influence of the popular sector of care on these children's life worlds.
The children's responses to the many questions posed to them about diabetes convey two life world's which parallel the disease/illness model. The children moved between these two models, and in part, their beliefs and behaviors were formed in an attempt to resolve the two viewpoints. The children present a disease model in the form of responses centered on their malfunctioning pancreas. In this orientation, they recognize that they have been diagnosed with a chronic, incurable disease which could prove to be fatal if they do not care for themselves properly. However, these children have taken a complex and often confusing disease and created a manageable illness, and therein lies the key. A focus on blood sugar regulation and symptom resolution creates a life world that is not so threatening. Imbalance episodes which are treated and ameliorated, primarily in the popular sector, help to convince the children that the condition is manageable. Children did mention other people who had died from diabetes, but attached a statement of qualification such as, "He didn't take care of himself."

Bluebond-Langner (1978) found in her study with leukemic children that tangible experiences with disease and illness were more important than chronological age. Diabetic children also accrue experiences through which they acquire factual information and learn to manage
their condition. The daily illness experience of diabetes, centered around management tasks, orients these children into health maintenance, not illness resolution perspectives. In general, adherence to daily maintenance tasks results in a lack of illness symptoms. When any individual takes actions to prevent illness it is seen as preventative, or health maintenance strategies. These diabetic children too view their daily diabetic-related tasks as directed towards health maintenance.

**Diabetic Knowledge**

These children's explanatory models reflect their interpretation of the information gathered from their health provider and parents but, perhaps more importantly, their daily popular sector experience with diabetes. The children offered a variety of explanations of etiology, onset, pathophysiology, and insulin function. Some of their concepts would be judged as inconsistent with biomedical models. Initial information about diabetes flows from the provider to the child (if the child is deemed old enough) and their caretaker. This professional model may receive reinforcement through future appointments or during resolution of imbalance episodes. However, the low rate at which providers were consulted in this sample would suggest that the more
dynamic development of the health/illness care model is taking place outside the professional sector of care.

Concepts about diabetic etiology and biology are abstract and often difficult to explain. Explanations about specific imbalance episodes are often more accessible and more relevant to these children. Although the ideal would be performance of management skills built upon a sound theoretical basis, it could be argued that many health promoting or illness mediating actions are undertaken by individuals of all ages without information on why these practices are effective. Health maintenance and illness resolution activities, based on empirical rather than theoretical knowledge (Young 1981, 1982a) are also employed by adults. Often there is not a clear understanding of the mechanisms that lead from a particular action to the cessation of symptoms. The continuation of the practice is supported by empirical evidence not theoretical knowledge. Although these children did not always offer biomedically correct explanations for the components of their illness states, this did not exclude their active participation in actions aimed at producing an amelioration of illness symptoms and a return to a healthy state.

Biomedical knowledge of the diabetic condition does not assure acceptance nor metabolic control. In turn, lack of knowledge does not necessarily translate into
poor management. Adherence has been linked to a belief that the individual could engage in behaviors to reduce the frequency of complications (Saunders et al. 1975). The empirical knowledge gained through daily management procedures and the avoidance of imbalance episodes may encourage adherence to a greater extent than an extensive theoretical knowledge base.

Diabetic Management

The vast majority of daily management care and imbalance resolution took place in the popular sector. These 26 children experienced 46 diabetic imbalance episodes and 15 non-diabetic illness episodes. A medical professional was consulted only four times in conjunction with imbalance episodes. This is less than Kleinman’s (1980) projected 10%-30% of illness episodes that enter the professional sector of care. These children are constantly being socialized into a role which gives them ultimate responsibility for their daily and long term health and illness states.

Participation in self care was evident in children as young as seven years old. These children with diabetes took an active part in their own health and illness care. They recognized the need for health promoting practices and were able to contribute to the
undertaking of these actions. Resolution actions for illness episodes were not performed randomly. Figure 1 graphically indicated that children utilized specific remedies in response to particular symptoms. Korbin and Zahorik (1985) also found that children differentiated specific remedies for symptoms. The children in the current study listed resolution strategies within their realm of control (i.e. food), and resolutions needing adult intervention (alteration in insulin dosage). There were times when the identification and resolution of an illness episode was undertaken by the child, without adult intervention. The children repeatedly reported a verification process for symptoms of imbalance. The first item in the hierarchy of response to a possible diabetic episode often was to obtain the objective measure of a blood sugar level.

Although management tasks are necessarily integrated into daily life, the children are very aware of the restrictions associated with these activities. They describe management of the diabetic condition as intrusive, citing interruptions in play and school. Their perceptions of a strict and regimented care schedule are reflected in their discussions. They describe their days as divided by hours, and listed associated tasks with those hours.
As the child enters the school system, management tasks must be adjusted accordingly. In addition, the child does not have the same access to parents, who acted as primary consultant at home. A child's social arena is centered on school. Many of the children's interactions with peers takes place in this academic setting. Pless and Roghmann (1971) observed that chronically ill children are at risk for poor academic achievement. Many of the children did list school as a stressor in their lives. This is probably true for ill and healthy children alike, because performance in school is a standard by which children are judged. Diabetic children must go beyond learning how to maintain physiological balance, to develop skills which can mediate the effects of the social world upon their physical and mental states.

**Coping Strategies**

Diabetes is a condition which is not outwardly apparent. These children can "pass" as normal because diabetes is not an "visible" affliction which immediately communicates that the individual possesses it (Goffman 1963). It is the behaviors resulting from management of the condition - the insulin injections, blood tests, dietary restrictions, schedule limitations and the
behavioral effects of imbalance - that indicate that the individual is different. These thoughts were voiced by the children in this study: "If I need to eat (in school) it bothers me. People ask questions." "When I go to a party I either take my own stuff or I don't eat." "I'll be having fun and I have to go in and get my shot ready."

Negative response to management procedures has been reported in other studies (Eiser 1985; Sperlich 1982), and seems to be a common complaint of diabetic children for both physical and social reasons.

Davis et al. (1965) report that, given the theoretical option of having diabetes or a more visible but less life-threatening condition, individuals chose diabetes. A similar pattern of acceptability was found by Eiser (1985). The children in the current study generally reflected this level of acceptance. Although the issue of visibility was not explored in depth, these children focused not on the issue of visibility, but on the manageability of diabetes as fostering their acceptance of the condition. The tension between the two life world perspectives, the very threatening disease model and the mediating illness model is illustrated by one child's view, "You can't eat sweets. In school you have to take snacks, people look at you. You can't be active in sports. You get sick. You always have to watch yourself closely. You are abnormal, but normal."
FUTURE RESEARCH DIRECTIONS

A specific goal of this research was to gain the perspectives of diabetic children. The rationale for this was that, for various reasons, children have been neglected as meaningful informants on their own health and illness states. The information gathered from these children should now provide the initiative for collecting additional information from parents, siblings, friends, and health professionals. This would expand the database, and provide a dynamic insight of the contribution of chronic illnesses to the creation of other life worlds.

Because the children in this study were diagnosed at least six months prior to the research, and received their initial diabetic education from various individuals, the effect of their educational experiences on their conceptualization and practice models could not be measured. Some of these children are active in diabetic support groups or various organizations affiliated with the American Diabetes Association. The affect of these factors need to be addressed when investigating health and illness beliefs and behaviors.

The original proposal for this study included a sample of newly diagnosed diabetic children. However, no
children in the stated age ranges were diagnosed during the study period. The opportunity to interview diabetic children when they are newly diagnosed and are rapidly incorporating new sets of medical and social experiences would be a valuable contribution to the study of diabetes and to the study of chronic illness in general.

We also need to investigate the beliefs, behaviors, and coping strategies associated with a lifetime of illness. Although these children realized that imbalance episodes were manifestations of a chronic condition, they often approached these episodes as a series of acute illness experiences. They were able to move between the perspectives of having a serious disease and/or a manageable illness. In addition, the concept of health should be expanded and further investigated. Given that on any one day we may experience countless states that fall outside our definition of health, perhaps in actuality, illness is our usual state with only limited forays into health.

Diabetes is a condition which clearly illustrates the importance of the popular sector of health care in the development of an illness model. Although diabetes is a disease which has been medicalized with official diagnosis and formal treatment plans arising from the professional sector, the vast majority of care is developed, maintained and evaluated in the popular sector
of care. With the recognition that only 10 to 30% of all illness episodes are brought to the professional sector (Kleinman 1980), it becomes increasingly important to understand the subclinical experiences contained within the popular sector of care. This information will provide insights to the health care patterns of chronically ill and healthy individuals.

A unifying factor for all chronic illnesses is self-care. These diabetic children reported an active participation in health care and illness resolution. Their participation included not only diabetic care, which in theory they are encouraged to assume, but responses to episodes of illness not arising from diabetic imbalance. Since self care is a strong component in the diabetic management scheme, do children with this chronic illness more readily assume responsibility for non-diabetic illness episodes? Do illness episodes which are not a direct effect of the diabetic condition remain in the popular sector longer than episodes of outwardly healthy individuals?

Research of cognitive explanatory models is fruitful, but investigation must move beyond conceptual models and explore the connection between theory and experience (Young 1981). Even in cases of recognized chronic illness, with participation in biomedical care, illness episodes may never enter the professional sector
of care. Patterns of conceptualization and behavior can only be researched by adopting a naturalistic perspective and eliciting information from individuals in their daily environment as they move through the life-cycle.

The school-aged years are rich in health and illness related issues. The heretofore neglected years from 6-12 emerge as fertile ground for expanded basic research (Shonkoff 1984:58). If we hope to understand adult beliefs and behavior patterns, we must begin by exploring the world of children. Patterns develop in the early years and are dependent upon a life-long conglomeration of experiences. It stands to reason that the children in this study will, in turn, influence their children’s health and illness concepts and behaviors. The dynamic process of developing health and illness beliefs, behaviors, and coping strategies should be explored further to enhance our understanding of how these experiences create and clarify meaning in the the lives of the chronically ill.
APPENDIX I

INITIAL INTERVIEW — JUVENILE DIABETES

_________________________ ______________________
(name) (date)

I’d like you to list for me the children that live in your house starting with the oldest and including yourself.

1. _________________________ ________(age) _____(sex)
2. _________________________ ________ ______
3. _________________________ ________ ______
4. _________________________ ________ ______
5. _________________________ ________ ______

Now, could you list the adults for me please?

1. _________________________ ________ ______
2. _________________________ ________ ______
3. _________________________ ________ ______
4. _________________________ ________ ______

I want to ask you some questions about how you think and feel. There are no right or wrong answers. I want to know what YOU have to say.

1. Why are you visiting here?

2. How often do you come here?
3. What do you call (answer given in #1)?
   (Is there a name?)

4. What is (name given in #2)?

5. How does it work?

6. How does the doctor say it works?

7. How do your parents say it works?

8. What cause (name given)?

9. Why do you think it started when it did?

10. Did you know anything about (name given) before you were diagnosed?

11. What were your initial thoughts when you first found out about (name given)

12. Who first explained (name given) to you?

13. What does this condition do to you? Physically? Mentally?

14. How do you know when you feel bad?

15. Is there anything you really don’t like about this condition? Is there anything that frightens you?

16. Is there anything you would like to do that you can’t?

17. Can other people tell that you have this condition? How?
18. What do your brothers and sisters think about your condition?
   Your friends?

19. Are there certain things you have to do to stay feeling good? (Check routines with actual management schedules if mentioned.)

20. What things do you have to do daily because of this condition?
   Insulin Who give you these shots?
   Daily tests How are these done? Who does them?

21. Have you tried both blood and urine testing?
   Do you prefer one or the other? Why?

22. Do these things make you feel better? Do you think they help you?

23. What would make you feel better (if no in #21).

24. When do you feel your best? Your worst?

25. How long will this condition last?

26. Is this a bad condition? Worse than a cold? Chicken pox?

27. What is the most serious sickness you have ever had?
WEEKLY_INTERVIEW -- JUVENILE_DIABETES

1. How have you been this past week?

2a. What did you do to stay healthy this week? Anything new?

2b. How did you know that something was wrong?

3. Could anyone tell that you were not feeling well?

4. Did you tell someone about it? Who? Who did you tell next?

5. What was the first thing that you did about it
   Did someone tell you to do that? Yes____ No_____ Who?
   Did you get better?
   How could you tell?

6. What was the next thing that you did?
   Did someone tell you to do that? Yes____ No_____ Who?
   Did you get better?
   How could you tell?

7. What was the next thing you did?
   Did someone tell you to do that? Yes____ No_____ Who?
   Did you get better?
   How could you tell?
8. What was the next thing you did?
   Did someone tell you to do that? Yes____ No____ Who?
   Did you get better?
   How could you tell?

9. What were you doing just previous to this episode
   (or word used by child)?

10. Do you have any ideas concerning why this happened?

11. Do you think this might happen again?
    Why or why not? How soon?
FOLLOW-UP INTERVIEW -- JUVENILE DIABETES

(Name)                     (date)

1. Have you attended diabetic camp?
   When?
   Why or why not return?
   Who made the decision that you would attend?
   Does it help you? Why?
   What did you like best about camp?
   Does it make a difference being around other diabetic kids? Why?

2. Do you feel different because you have diabetes?

3. Is there anything your family does differently now than they did before you found out that you had diabetes?

4. Is there anything that having diabetes interrupts?

5. When exactly did you find out about your condition?

6. Are there any other names (labels) for diabetes?

7. What causes diabetes?

8. How does diabetes work?

9. How does insulin work?
10. How often do you take insulin?
   What dosage do you take?
   What type do you take?
   Does someone give it to you or do you do it yourself?

11. What kind(s) of tests do you do?
   How often do you do them?
   Who does them?
   Who reads (interprets) them?

12. Are there times you change your routine?

13. Do you get your doctor’s or Peggy’s permission before you change your routine?

14. Do you think you need to come to the clinic when you do?

15. Does Peggy or your doctor spend enough time talking with you?
   Do you understand what they say?
   Do they answer your questions?
   (Do they explain enough?)

16. Can you remember your worst reaction or when you felt the very worst?
   How old were you?
   Where were you?
   What were you doing just before it happened?
   What was the first thing that you did about it?
   Did someone tell you to do that? Yes ___ No ___ Who?
   Did you get better? How could you tell?
17. How do your parents react when you have a reaction or feel bad?
   
   How do your brothers or sisters react?

18. How many times have you been in the hospital?  
   For what reasons?

19. Could you list for me the top three stressful things in your life?
   
   1.  
   2.  
   3.  

20. Would you list the top three stresses for you having to do with your condition?
   
   1.  
   2.  
   3.  

21. What is the best part about being a diabetic?

22. Does your family have a religious preference?  
   (Does your family attend a specific church or temple?)

23. Would you say that your family is religious? Why?

24. What are your plans for the future?

25. What do you think about this study?  
   Do you thing it will be useful?
Appendix II

Multi-dimensional Scaling -- Figure I

A computer program, ANTANA, was used to create the figures in this dissertation. For Figure I, each child was contacted weekly and information was gathered on any illness episodes. A total of 46 diabetic imbalance episodes and 15 non-diabetic illness episodes were collected. The symptoms the children listed in response to "How did you know something was wrong?" and the action taken in response to these symptoms was coded and entered into the computer. At times, the children listed more than one response to a symptom, or to several symptoms which were judged to be in the same category. In this case, the symptom(s) were coded once, and each response was coded separately, resulting in more than 61 recorded pairs of symptoms and responses. In this manner, ordinal data was created out of the children's verbal information.

The children used many terms to describe their symptoms and responses. These answers were categorized by the principal investigator. The pre-categorized answers are listed below, along with the number of times each answer was given. This data does not assume action independent of an adult.
SYMPTOMS

Weakness/Pain n=39
- shaky
- tired
- weak
- tingly
- stomach ache
- hungry
- legs give out
- can’t see well

Diabetic Reactions n=20
- unconscious
- convulsion
- indicate by blood test
- use bathroom a lot

Mood Alteration n=6
- acting weird
- acting nasty

Cold Symptoms n=14
- cough
- throat hurt
- stuffy nose
- lots of phlegm
- itchy (non-diabetic)

Headache n=8
- headache

Mental Confusion n=6
- dizzy
- room spinning

RESPONSES

Consumption n=40
- take sugar/glucose
- eat sweets
- eat food
- drink
- eat and drink

Insulin Management n=12
- increase insulin
- take shot
- do a blood test

Medicines n=17
- take (list of medicines)
- take medicine
- take vitamins
- drops in eye

Alter Behavior n=6
- exercise
- go in the shade
- go to the bathroom
- avoid sibling

Seek Health Professional n=6
- go to the hospital
- see the doctor
- see the nurse (at an amusement park)

Rest n=12
- rest
- nothing/rest
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