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ANN HARLAN

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RENA D. HAROLD
Major professor

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GENDER AND AGE COMPARISONS FOR ADOLESCENTS WITH DIABETES

By

Ann Harlan

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ABSTRACT

GENDER AND AGE COMPARISONS FOR ADOLESCENTS WITH DIABETES

By

Ann Harlan

Adolescence is a time of turmoil that for some teens is compounded by caring for insulin dependent diabetes mellitus. Gender and age comparisons are missing from the literature to ascertain differences in the functioning and difficulties faced by adolescents with diabetes. This research project as an exploratory study to assess age and gender differences in teenagers 13-18 years old who attended the Michigan State University Pediatric Diabetes Clinic. Quantitative data were drawn from patient charts of 93 adolescents. Average glycohemoglobin results for one year were used as a measure of diabetic control. Qualitative data was used to enhance an understanding of the factors playing a role in the lives of the subjects. This was accomplished through in-depth interviews of a subgroup of those in good and poor control. Although there were no statistically significant differences in gender or age groups, the analyses revealed that most of the subjects, regardless of age or gender, were in poor control of their diabetes. Issues that were relevant included those in poor control who appeared to have an inaccurate

understanding of their diabetes, and its effect on their health (whether through lack of education or denial) and those in good control who reflected a sense of acceptance and responsibility for their diabetes.

DEDICATION

I dedicate this document to God, my dear friend, Diane Genshaw, my love, Howard Sanderlin, my precious son, Kyle, and all my wonderful friends. Without them, I am nothing.

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I wish to thank my dear friend, Diane Genshaw, for her loyalty and assistance in this project. The countless hours of help will never be forgotten. She can have any of my spare organs, should she need them.

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To Kyle, my son, thank you for your understanding and patience when I had so many deadlines to meet. No one could ask for a better son.

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CHAPTER I

INTRODUCTION

Introduction

Adolescence is a time of transition that involves many facets and may include great turmoil. This can include physical development, hormonal shifts, social transition to adult roles, and the accompanying emotional changes (Elliott, Feldman, & Feldman, 1990; Lerner, 1987, 1991; Lerner & Spanier, 1980; Peterson, 1988). Social scientists and others have studied this portion of the life cycle from various perspectives such as family interactions and communication patterns, peer relationships, development, and sexuality (Brooks-Gunn & Furstenberg, 1989; Brooks-Gunn & Peterson, 1983; Furstenberg, Levine, & Brooks-Gunn, 1990; Hauser, Powers, Noam, Jacobson, Weiss, & Follansbee, 1984; Lerner & Knapp, 1975). One of the subgroups that has been studied is the adolescent who has chronic illnesses. Within this subgroup are adolescents with diabetes (Borenstein, Harvilchuck, Rosenthal, & Santelli, 1996; Cadman, Boyle, & Offord, 1988; Campbell & Patterson, 1995; Kallen, 1984; Meijer & Oppenheimer,1995; Merkens, Perrin, Perrin, & Gerrity, 1989).

Adolescents with insulin dependent diabetes mellitus (IDDM) present as a particularly challenging group to parents, medical providers, social scientists, and others who play a role in their development or caregiving. The usual development of the teen years is certainly compounded by facing a continual medical condition that is potentially life threatening.

This research project focused on the adolescent with diabetes, with an emphasis on the differences that might appear in the control of diabetes in males and females throughout the teen years. There was a fairly substantial amount of research on adolescent with diabetes (Amiel, Sherwin, Simonson, Lauritan,. & Tamborlane, 1986; Grossman, 1987; Hanson, Henggeler, & Burghen, 1987; Hauser, Jacobson, Lavor, Wolfsdorf, Herskowitz, Milley, Bliss, Wertlieb, & Stein 1990; Kovacs, 1979; La Greca, 1982; Marrero, Lau, Golden, Kershnar, & Myers, 1982; Peveler, Fairburn, Boller, & Dunger, 1992;). However, one facet that had little information was that of a comparison between males and females with diabetes. Research had been done about differences between males and females on topics such as learning, and communication, and these will be addressed in subsequent sections. It is expected that by examining the previously stated differences between the genders and applying these differences to the complex life of the adolescents who have diabetes, there should be a better understanding of their lifestyle. This better understanding should lead to improved interventions to assist teens with diabetes and their caregivers.

Background Information

Diabetes

IDDM is one of the major chronic illnesses that affect the health of children with 1.8 in 1,000 children having this condition (Perrin, 1992). Every year in the United States, 11,000 to 12,000 children are diagnosed with IDDM (U. S. Department of Health and Human Services, 1994). It is one of the most common childhood illnesses.

Diabetes mellitus is:

> A disease that occurs when the body is not able to use sugar as it should. The body needs sugar for growth and energy for daily activities. It gets sugar when it changes food into glucose (a form of sugar). A hormone called insulin is needed for the glucose to be taken up and used by the body. Diabetes occurs when the body cannot make use of the glucose in the blood for energy because either the pancreas is not able to make enough insulin or the insulin that is available is not effective (U. S. Department of Health and Human Services, 1994, p. 5).

Prior to the discovery of insulin, children with IDDM died prematurely and suffered from growth retardation (Clarke, Vance, & Rogol, 1993). Since it has become standard procedure to use insulin to treat IDDM, inadequate growth is uncommon. Furthermore, currently over 90% of children with IDDM are expected to survive into adulthood (Orr, Fineberg, & Gray, 1996). These data offer hope to a current generation of teenagers who suffer from diabetes.

Non-insulin dependent diabetes mellitus (NIDDM) is considered a separate disease from IDDM that generally affects adults who are overweight. Although adolescents can occasionally have NIDDM, it will not be addressed or included in this paper to maintain the focus on the more prevalent and serious chronic illness of IDDM.

Medical Advances

The effects of a lack of insulin were first recognized in 1889 in Germany through observations in animal research after a total pancreatectomy. Interestingly, an adolescent was the first human ever recorded to have received any treatment for diabetes. Pancreatic extract was first injected into a human (a 14 year old boy) in 1922 in Toronto. Insulin was distributed in most Western countries by the end of 1923 to safely and effectively treat diabetes (Bliss, 1993). Insulin is now administered at home by the adolescent, family or caregiver through injection and is considered standard treatment for IDDM.

The most important contribution to the care of IDDM after insulin was the invention of the portable home blood glucose monitor (HBGM) or glucometer. This electronic devise allowed people with diabetes to test their blood glucose at any moment in time to monitor the current blood sugar. These instruments are fairly inexpensive although the test strips used 3-4 times a day are costly. The HBGMs were tested and shown to be as accurate as laboratory testing to measure blood glucose (Tate, Clements, & Walters, 1992). This was important because adolescents with diabetes could monitor their blood sugar and change insulin on a regular basis, which provided better diabetes care and decreased the chances of both short and long term complications (U. S. Department of Health and Human Services, 1994).

Blood tests called glycohemoglobins (glycos) are currently utilized to determine overall control of diabetes. This test is conducted in a laboratory or medical clinic and gives a percentage of blood sugar that represents a 2 to 3 month period of time. This number is utilized to determine the level of diabetes control with higher numbers demonstrating more poor control. At the Michigan State University (MSU) Pediatric Diabetes Clinic a non-diabetic range is 4.8% to 7.8% which is consistent with the national standards (Anderson, Anderson, & Glanze, 1994; The DCCT Research Group, 1988, 1996)

Age, Gender and Diabetes

Diabetes is an important disease to study as it is a potentially fatal condition when not treated adequately (Anderson, Anderson, & Glanze, 1994; Bliss, 1993). This section will address some of the relevant age, developmental, and gender issues.

This research entailed looking at adolescents with diabetes and determining whether there were age and gender differences. There was an accent on the overall issues within age and gender that might have played a role in both variables. The focus of the tasks of adolescents for identity and invulnerability, peer pressure, and social influences all played a role in the possible difference in the research subjects and are discussed in Chapter 2 (the Literature Review).

Purpose of the Study

Because of the complexities of the care of diabetes combined with the developmental issues of adolescence, it was important to determine how adolescents were managing diabetes. In order to provide optimal care for the adolescent with diabetes, it was critical to look at the differences between the males and females in relationship to their management of diabetes care. Age, which for the purposes of this study was limited to chronological, was also included in this assessment to determine whether it had an impact. It was decided by this researcher to divide the sample group into three categories in which there are two years in each category as there are developmental differences between younger and older adolescents (Cole & Cole, 1993; McGraw, 1987; Peterson, 1987). In this researcher's opinion these categories reflected early, middle, and late periods in adolescence. The three age groups were: early (13-14 year olds), middle (15-16 year olds), and late (17-18 year olds). These categories were chosen to attempt to determine whether there was a difference in control of diabetes by age.

The literature did not demonstrate any empirical determination of whether adolescent males or females had a more difficult time controlling their diabetes, so it was not possible to presume what information might be gleaned from this project. However, it was clear that there was a need to determine what was taking place with adolescents with diabetes and how the gender and age differences might have played a role.

The motivation for this study stemmed from the clinical experience of staff at the MSU Pediatric Diabetes clinic and their discussions about the differences in adolescents with diabetes. Several staff members had speculated that females had more difficulties than males in controlling their diabetes. No research on this topic had been conducted at this setting to determine whether it was accurate, and it may have been a clinical bias based on the focus of problems on a small number of troubled females. This research project was designed to assist in determining whether such a difference existed.

The most prevalent need for this study resided in the lack of existing data to assist health care providers in determining what is taking place in the lives of the various subgroups of adolescents with diabetes. Clinical experience was important in formatting research questions as the current literature lacked substantiation of gender and age differences in adolescents' control.

Further need for this study was presumed based on the evidence of the complex life that faced adolescents in our society as previously noted. This study will provide additional information about the teen years to expand upon the existing research. Adolescence is generally considered a challenging time with many internal struggles (such as the conflict in the quest for autonomy), social impacts (such as peer pressure), and environmental factors (such as laws governing the limitations of the teenager's ability to work and be independent). For the adolescent with diabetes, normal adolescent traits and struggles could be complicated by the care of an illness. Research noted in the literature review in Chapter 2 of the project has aided in the understanding of what is happening to the adolescent with diabetes. However, again while many of these factors have been researched, a basic understanding of the interaction of age and gender for adolescent males and females with diabetes has been overlooked.

This project addressed this aspect and examined quantitative data to see whether there were differences in the subgroups. Based on the results of the quantitative data, qualitative interviews were conducted to enhance the results. The qualitative portion is explained in more detail in another section. It is the researcher's hope that this information will provide a foundation for future research to build upon the noted differences in control of diabetes to assist in providing services that will ease the adolescent's struggles and increase their quality of life. The purpose of this study was to set the groundwork for future research through this exploratory project, and to develop empirically based interventions for this population.

Relevance of the Study to the Field of Social Science

Social Science frequently studies subgroups of people in order, to identify problem areas and to offer explanations of how events impact the lives of the people involved. It was hoped that this research project would offer insight into gender and age categories that might indicate subgroups with more significant problems controlling diabetes and lead to the development of interventions that might assist those that were having difficulties. The social sciences have historically had a great impact on many aspects of medical care (Glassner, 1981; Hollingshead, 1973). Working together with health professionals could increase the quality of care through attention to a gender and/or an age specific approach to diabetes education, counseling, physical examinations, and support groups. For example, if it was determined through quantitative analysis that females have a more difficult time controlling diabetes, the qualitative research might assist in determining what was interfering with the ability of females to conduct diabetes care. This might lead to recommendations for an approach such as incorporating information on eating disorders during diabetes education.

Theoretical Base of the Research

Social science is composed of a systematic organizing of concepts to provide a framework to understand some aspect of social functioning. In the discipline of medicine patient behaviors were often studied by social scientists (Glassner, 1981; Hollingshead, 1973). Several theoretical approaches have been developed over the years to understand and sometimes predict patient behavior. Historically the traditional Medical Model, dominated the health field for many years (Freeman & Levin, 1989). It was based on a focus on pathology with a belief that health was beyond the control of the patient. Parsons' (1951) "sick role" exemplified this in that the physician provided care to the helpless patient. The more contemporary models of the Compensatory Model and Health Belief Model from the health and social science fields were a more appropriate basis for this study.

The Compensatory Model (Becker & Rosenstock, 1989) focused on individual power in health behaviors. It did not blame the patient for their illness but rather expected the patient, at least in part, to be responsible for their recovery, or to compensate for the handicaps that were side-effects of the illness.

The Health Belief Model, which grew out of health education programs, began by trying to determine why people behaved as they did, particularly in conducting or avoiding preventative health behaviors. A commonly cited example was that of immunizations. Because of the importance of immunizations in preventative health care, many studies were conducted to determine why certain people obtained immunizations for their families, with correlations for beliefs and intentions (Kirscht, 1988; Rosenstock & Kirscht, 1979).

Both the Compensatory Model and Health Belief Model focused on the role of prevention (Becker & Rosenstock, 1989; Kirscht, 1988; Rosenstock & Kirscht, 1979;) Prevention was of particular importance for those who had diabetes. For example, regardless of whether or not they were effective, adolescents with diabetes generally took an active role in the care of their disease. When an adolescent was having a low blood sugar episode, they treated it by ingesting some sugar or juice. Teenagers generally moved from one activity to another, and were not overseen on a continual basis throughout the day by their parent and/or teacher. Furthermore, these incidents were sometimes unpredictable and had to treated as they arose. This treatment demanded an active, preventative involvement on the part of the patient. The two approaches used in this research placed no blame on the teenager for their diabetes, but showed an underlying understanding that they were responsible for some aspects of their diabetes care in that they were physically and emotionally capable of conducting blood sugar tests and giving insulin injections. Included in this were the assumptions that the adolescent and/or their family was involved in regular doctor's appointments, blood sugar tests, and insulin injections that were considered not only preventative but also necessary components of diabetic care.

The Research Question

This research project was an exploratory project that involved reviewing patient charts to assess the possible difference between gender and age in regards to control of diabetes for adolescents. In the absence of any definitive research, the initial research question was whether gender made a difference in control of diabetes. Furthermore, there is often a vast difference between younger and older adolescents in terms of their development, so the second research question was whether age made a difference in control of diabetes. There were five hypotheses offered in the quantitative part of this research project:

Hypothesis #1:

There will be differences between control of diabetes for adolescent males and females, based on the results of their glycohemoglobins.

Hypothesis #2:

There will be differences in age categories (i.e. early, middle and late adolescence) in control of diabetes between male and female adolescents, based on the results of their glycohemoglobins.

Hypothesis #3

There will be differences in the interactive effect between age and gender, based on the result of the glycohemoglobins.

Hypothesis #4

There will be differences in gender for dichotomous glycohemoglobins levels of equal to or less than 10% or greater than 10%

Hypothesis #5

There will be differences in gender or age categories for independent variables of gender, age, length of time with diabetes, and number of glycohemoglobins obtained.

Limitations of the Study

Because this study was exploratory, there were many possible limitations that were present. First, the patients who attended the clinic might not be an adequate representation of a population of adolescents with diabetes. The population consisted mostly of those who lived in the greater Lansing area and those from rural areas might not be adequately represented.

Second, because a pediatric subspecialist is an expensive service, those who attended the clinic generally either had health care benefits or were able to afford the extra cost involved in seeing a specialist. While Medicaid patients attended the clinic, those who did not qualify for Medicaid and did not have commercial insurance would not likely attend this setting. Therefore, the working poor might be missed in the sample.

Third, the laboratory tests were accumulated from the results of 1996 and represented only one year of information, not test results over several years in the life of each individual. Longitudinal information might have offered more rich data on the fluctuation of the glycohemoglobins over the adolescent years. However, it is hoped that by sampling the different age groups, this provided adequate information to determine if there were differences in groups.

In spite of the limitations of this research, the purpose of the study was to present a snapshot of what was taking place in the lives of adolescents with diabetes. Hopefully, this study will offer information that will direct future research to areas that will assist the adolescent with diabetes.

This project included both quantitative data and qualitative data. The quantitative data was drawn from clinical charts from the Michigan State University Pediatrics Diabetes Clinic and the qualitative data was derived from a selected sample of the subjects from whom the quantitative data was obtained. Chapter 3 describes the design of the study in detail.

Summary

In this chapter, the purpose for the study was stated as to determine if there were any differences in managing IDDM between and among male and female adolescents. Further, the purpose of the study was to set the groundwork for future research about male and female adolescents with diabetes. The need for the study was established by indicating the lack of information about comparisons of adolescent males and females in the literature. Relevance of the study to the field of social science was highlighted by defining adolescents with IDDM as a population subgroup. In particular, subgroups with medical problems were studied by social scientists who historically have had great impact on many aspects of medical care. The theoretical bases of this study resided in Parson's "sick role", the Medical Model, the Compensatory Model., and the Health Belief Model. The research hypotheses were given. This research was presented as an exploratory study. Limitations of the study were related to the population, the methodology and the procedures.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

The first part of this literature review discusses how the literature was searched. Next, the developmental tasks and roles of adolescents and how these are affected by the diagnosis of IDDM are examined Then psychological and social factors in diabetes care are investigated. In this section, special attention is given to differences between males and females in regards to the management of their disease. Next, family culture and dynamics are reviewed to see how parenting practices and management of the diabetes are intertwined. Finally, how the community impacts the adolescent with diabetes, and how the adolescent with diabetes is impacted by the community are explored.

Literature Search

An intense literature search was conducted of both medical and psychosocial data bases for current information on adolescents with diabetes. The search was generally limited to the previous 10 years to obtain recent findings as medical care for Type I diabetes has changed dramatically since the invention of the glucometer discussed earlier. Keyword such as adolescence, diabetes, teenager, and glycohemoglobin were utilized. Literature bases included Medline, Health Star, Psychlit, and Sociology and

Social Work Abstracts. Journals that are specifically written for patients and health care providers on diabetes were included. All articles on Type II diabetes were eliminated. Articles that were found that discussed adolescents with Type I diabetes were included in this research project. Staff at the MSU Clinical Center provided some guidance into the search with articles that they had accumulated about particularly relevant issues. For instance, The DCCT research (The DCCT Research Group, 1995, 1996) was generally conducted on adults with Type I diabetes, and yet the results of that research demonstrated that by increasing the number of tests that were conducted in a day (to at least three a day) and redistributing insulin to smaller doses more frequently (usually from two to three or four shots a day), the subjects showed a dramatic improvement in diabetes control which decreased diabetic complications over a long period of time. This was particularly important as the MSU Pediatric Diabetes Clinic has recently incorporated the results of this research into practice and has switched many adolescents from two to three shots a day (B. E. Wilson, personal communication 1996).

Developmental Tasks and Role of Adolescents

Young, Anderson & Steinbrecher (1995) argue that, "Psychology has traditionally undervalued adolescence as a transitional period between childhood and adulthood, rather than viewing it as a distinct entity in its own right, and this perspective has flavored adolescent assessment, diagnosis, and intervention (p. 343). They argue that adolescents often present with different symptomatology than children and adults and cite the example of anger and acting-out as a sign of depression as opposed to adult symptoms like difficulties with sleeping, eating and crying. Included in this is the fact that these needs are not addressed adequately because of a lack of attention and services designed for their unique place in the life-cycle. Furthermore, Takanishi (1993) argues that currently teens are presenting with mental health needs at alarming rates. For adolescents with substance abuse and mental health needs, the lack of the ability of adequate research and mental health services to cope with these, makes it more difficult to serve adolescents with diabetes.

Erikson's (1968) work on adolescence highlights the important task of establishing an identity during this stage in the life-cycle. This theory focuses on a physical and emotional crisis in which positive resolution results in a sense of identity while the inability to adequately maneuver through this stage results in role confusion. Included in this stage is the focus in our society on males being encouraged to be competitive and pursue a career while females are encouraged to be more passive and make themselves attractive to males for future partners, as opposed to planning for a career (Tischler, 1996). The crisis that arises in the quest for identity may be negatively impacted by a chronic illness. For instance, a 15 year old may desire to try out some new independence by earning money through baby-sitting. This may be prohibited by either set of parents as they may worry that the teenager will have a blood sugar reaction and be incapacitated while attending to younger children. Although baby-sitting might be viewed as a normal "right of passage" for this age, this teen may be not permitted to pass through this new step in his or her search for autonomy.

Included in adolescence is a time that is marked by feelings of invincibility when the teenager does not believe that the consequence of some action or some situation will occur to them. The development of the adolescent to Formal Operations (Inhelder & Piaget, 1958; Piaget, 1970, 1972) is striking in that the teenager discovers that there is a cause and effect relationship but also that effects may take time and not be an immediate reaction. If the adolescent has not reached the stage of Formal Operations Stage, she/he may delay appropriate diabetes care especially the taking of blood tests. Physical reactions or discomfort often do not immediately follow inappropriate amounts of insulin. Even if the adolescent has reached the stage of Formal Operations he/she may avoid blood sugar tests and continue to give a set amount of insulin because it is easier than testing regularly and adjusting insulin or because they can avoid facing their own vulnerability by not attending to their disease. The Formal Operational Thought Stage is generally a feature of early adolescence and may begin in the preteen years however, it is more developmentally dependent rather than age dependent and some teens may not reach the Formal Operations Stage until adulthood. The Formal Operations Stage is an important milestone in that the adolescent can think abstractly and see the consequences of their action or inaction. Subjects for this study were selected at 13 years of age and older because it was presumed that most of them would be able to think about the future and already have incorporated the consequences of attending to or avoiding care of the diabetes. Clinical experience and heuristics about teenage behavior lead to the anticipation that despite their ability to understand the consequences of their actions, many of the teenagers may not be controlling their diabetes well (Golden, Herrold, & Orr, 1985; Ingersoll, Orr, Herrold, & Golden, 1986) . This, in part, may be due to inability or unwillingness to think about the future.

Adolescence is a time when an individual often feels free from the burdens and responsibilities of adulthood and looks forward to planning a future with many hopes and aspirations. A chronic illness, such as diabetes can interfere with this plan. Whether or not an adolescent is able to face this condition and its ramifications or not, diabetes highlights one's frailty or mortality. To confront diabetes during this optimistic time in life can be very difficult. It is essential to study the issues of the adolescent combined with those of the care of diabetes to understand how they interact in order to plan for appropriate treatment based on the needs of the subgroup. The importance of the interaction of physical and emotional development with chronic illness has been recognized particularly as it relates to larger institutions, such as hospitals. Kallen (1984) has noted,

> The central task of adolescence - resolution of conflict between autonomy and dependency, the development of intimacy and competence, the ability to take on adult roles, and the development of the self - may be hampered by a total institution which depersonalizes patients and fosters dependency (p. 78).

The adolescent with diabetes interacts with medical facilities much more than the teen who does not have a chronic illness. Based on Kallen's and other's work, it is speculated that, the development of the adolescent with diabetes may be impaired through the depersonalization and dependency that stems from their reliance on medical care.

Peer pressure plays an important role in the development of the adolescent. As they strive for autonomy from their family, their peers' influence increases (Savin-Williams & Berndt, 1990). Research shows that there are differences in ages for adolescents in their susceptibility to peer pressure. Younger adolescents are more vulnerable to peer pressure than older adolescents (Berndt, 1989; Bixenstine, DeCorte, & Bixenstine, 1976; Collins, & Thomas, 1972). In the United States, teenagers average 20 hours outside of the classroom with peers, which is a major contrast to the two to three hours of time spent with peers in Japan or Russia, and furthermore, the time with peers increases with the age of the adolescents (Csikszentmihalyi & Larson, 1984). Being prone to peer pressures may be mediated in the younger adolescent by more parental restrictions. However, older adolescents spend more time with peers, and utilize their peers to try on new identities, it is logical that older teens would be greatly impacted by their friends. Despite younger adolescents being more susceptible to peer pressure, the older teens may risk getting into more serious difficulties as they have more freedom. For example, a 16 year old adolescent may drive a car while drinking while a 14 year old who drinks will generally have less access to a vehicle to cause an accident.

There has been a marked increase in problems among adolescents as demonstrated by increases in eating disorders, smoking and the use of drugs, sex at younger ages, and violent behavior (Blumstein, Cohen, Roth, & Visher, 1986; Elliott, Huizinga, & Menard, 1989; Kandel, 1980; Kandel, Davies, Karus, & Yamaguchi, 1986; Lucas, Beard, Kranz, & Kurland, 1983; National Institute of Drug Abuse, 1987; Strober, 1986). This increase allows for many negative social influences to permeate the environment of the adolescents. For those with diabetes, this can greatly impact their health. For example, the use of drugs may impair the adolescent's ability to care for their diabetes as their blood sugars fluctuate under the influence of the drugs or the concentration of sugar in the alcohol. Additionally, they may become unable to attend to the diabetes because they are high, drunk or unconscious. This may partially account for differences in diabetes control that may be present in older adolescents.

Adolescent girls report more concern about their appearances than do their males counterparts (Violato, & Holden, 1988). This information is consistent with the other research about the modern social pressures on women to be thin. This concern often leads to eating disorders for women (Boskind-White & White, 1986;; Brumberg, 1985; Lucas, Beard, Kranz & Kurland, 1983 Strober, 1986). This addition of problematic eating behaviors and thinness can negatively impact diabetes as blood sugars fluctuate dramatically during binging and purging as well as during times of restricted eating. This again may play a role in the possibility of female adolescents having poor glycohemoglobins.

There are many influences on adolescents. Developmental and social pressure that impact older adolescents in their movement toward autonomy and adult roles may be interrupted by diabetes. For females, the added pressures of trying to be thin can cause eating disorders. Often their focus is on the way that they look because they feel they must be thin to develop relationships with the opposite sex. This leads to the speculation that older adolescent females may be in less control of the diabetes.

When an adolescent is diagnosed with diabetes, they may have previously been a healthy individual with no family history of IDDM. It is often a shock for the family to discover that their child has this chronic illness through a trip to the emergency room when the adolescent becomes seriously ill. After the initial trauma and stabilization of the teen, the family is generally instructed in the care of diabetes by the hospital staff. They are then sent home with the expectation that they will make adjustments in their lifestyles to accommodate the diabetes regimen.

The treatment of diabetes always involves taking multiple blood tests through finger pokes and administering insulin on a daily basis. Hypoglycemic or low blood sugar episodes are to be monitored and the adolescent is given sugar when their blood glucose level falls too low. To miss treating an episode means that the adolescent is at risk for going into a coma from insulin shock, and perhaps dying. Hyperglycemic or high blood sugar episodes are when the patient has blood sugar levels that are too high. This may happen when the adolescent becomes ill with conditions such as influenza, or by not getting enough insulin. Hyperglycemia can lead to diabetic ketoacidosos (DKA). During DKA, the patient must receive insulin to allow energy to get into the cells and take extra fluid to assist in flushing ketones from the urine. In acute hyperglycemia, the patient risks going into a coma and possibly dying. In chronic, lower levels of hyperglycemia, the adolescent risks developing kidney failure and eye damage, and over time, may die prematurely (U. S. Department of Health and Human Services, 1994).

The adolescent and family are required to maintain a blood sugar level range that will avoid hyper- and hypoglycemic conditions. Unfortunately, insulin is a hormone that interacts with the human body, and responds to other hormones, such as those that are fluctuating during puberty. It also interacts and responds to body changes, like increases or decreases in exercise, food consumption, and positive and negative stress (Clarke, Vance, & Rogol, 1993; Golden, Herrold, & Orr, 1985). The family's quest to maintain blood sugar levels becomes a complicated process. An adolescent who stays after school to participate in a play or basketball practice may miss a snack. A teen without diabetes who misses this snack may merely go hungry while a teenager with diabetes may lapse into a coma from a low blood sugar episode. Similarly, a common teenage behavior of sleeping in on Saturday mornings is no longer a viable option to those with IDDM as they must get up, test their blood sugar, give an insulin injection and eat near to the normal awakening time.

Review of the Literature

As is evident, the adolescent's lifestyle is permanently altered by the diagnosis of diabetes. Even if s/he is able to maintain appropriate blood sugar levels, the cost of this process is that s/he must always be diligent about attending to the diabetes regimen. To miss one insulin injection may mean that the adolescent ends up ill or in the hospital, (Clarke, Vance, & Rogol, 1993; Golden, Herrold, & Orr).

Diabetes causes adolescents to make extreme changes in their lifestyle. They have to adjust to incorporating a regimen that means getting up at about the same time every day, testing blood sugar levels several times a day, giving insulin injections at least twice a day, going to the doctor's office more frequently, undergoing regular laboratory tests, carrying sugar products to treat hypoglycemic episodes, and making sure that insulin is adjusted regularly to avoid high and low blood sugar levels. In addition, the adolescent must now transpose all of this information and diligent work onto the physical, emotional, developmental, and psychosocial factors that may be taking place. Then they must integrate all these factors when dealing with their family, home, school, peers, and community (Clarke, Vance, & Rogol, 1993; Golden, Herrold, & Orr, 1985. The next section will address the added complication that the teen with diabetes must now face and how these interact with diabetes care.

Psychological/Social Factors Affecting Diabetes

Controlling diabetes can be a complicated process. For the adult, this regimen can be challenging, but often more so for the adolescent, who may not be able to cope with adult responsibilities or to face the need for this attention to health care when they are at a developmental stage that demonstrates their feelings of invincibility and unwillingness to think into the future.

Adolescence is a time of change and the growth, developmental and psychosocial factors that play a role in this portion of the life cycle probably contribute to some difficulties in diabetes management. Interestingly, while age or maturity may play an important role in the adolescent's ability to control diabetes, no studies were found that compared the younger and older adolescent in relationship to their abilities to manage their diabetes care.

The following literature review focuses on studies that are about adolescents with IDDM. The information presented here is a summary and synthesis of the research. The topics were categorized in a style based on the model by Bronfenbrenner (1977), which begins with a microsystem view of individual issues, advances to the linking to mesosystem family issues, and finally addresses the exosystem which are those components in which the adolescent does not participate directly.

Individual Attributes and Idiosyncrasies

Psychosocial Factors

Many psychological factors that directly affect the adolescent on an individual basis show up in the literature (Grossman, 1987; Hanson, Hengeler, & Burglen, 1987; Hanson & Prichert, 1986; Thornburg, 1982; Wysocki, 1993). Depression, stress, communication and conflict resolution skills, social competence, self-esteem, and peer pressure will be addressed in this section. Due to the prevalence of eating disorders among this population, special attention will be placed on this component (Felts, 1996; Fodor & Thai, 1984; Peveler, Fairburn, Boller & Dunger, 1992; Stuart & Jacobson, 1979).

As early as 1979, Kovacs noted that depression was seen in the adolescent newly diagnosed with diabetes and this was attributed to a mourning reaction as part of their grief process. However, Grossman (1987) later attributed the depression to the adolescents' belief that they did not have any control over the disease (external locus of control) combined with a low self-esteem. Depression influences individuals in different ways but can certainly interfere with a person attending to personal or medical care. It may cause teenagers with diabetes to neglect the regimen needed to control their diabetes

Teenagers' abilities to cope with normal activities of daily living vary. Some adolescents are able to accept responsibility at much younger ages than others. This variation obviously may be reflected in their diabetes care. For example, in a study of 39 adolescents (12 to 15 years old) who attended a summer camp for children with diabetes, there was a significant impact in better diabetes control among those who had better coping strategies for minor daily stress These strategies included their ability to problem solve effectively and good communication skills (Hanson & Pichert, 1986).

Other skills are also relevant to good control of the diabetes. A study was conducted with 115 adolescents with IDDM that indicated that good communication and an ability to resolve conflicts effectively, positively impacted the adolescents ability to have good control of the diabetes (Wysocki, 1993). In a study by Hanson, Henggeler and Burghen (1987) of 104 adolescents who displayed high social competence under stress there were no linkages with poor metabolic control and stress. However, those with poor social competence combined with stress were correlated with poor metabolic control.

Compounding diabetes care is the turmoil that faces the adolescent during the teen years. Fluctuating hormones and emotions may cause mood swings. Conflicts with parents and authority figures are common among adolescents as they try on different roles to establish an individual identity, struggle with "goodness of fit", and wrestle with their shifting moods. In the past, adolescents who were involved in lying and stealing were considered maladjusted or even considered to have personality disorders. However, more information has led to the realization that such behaviors may be "peer induced, sanctioned, and reinforced" and that they may be a part of the normal "range of functioning" for adolescents (Thornburg, 1982). Some teens present false blood sugar numbers or refuse to participate in the blood tests.

While deceptions and resistance may be part of the adolescent peer culture, they make diabetes management more difficult. Misrepresenting blood sugar numbers to parents or medical personnel can lead to increased conflicts as the false information is discovered and the teenager is confronted. Based on the clinical experience of the MSU Pediatric Diabetes Team, it is not unusual for teens to give inaccurate blood sugar numbers. Whether this is to make parents happy, avoid dealing with the diabetes, or some other reason, it inevitably causes conflicts as parents attempt to determine the truth.

As noted above, stress, coping abilities, locus of control, self-esteem, social competence, communication, conflict resolution skills, and peer pressure all contribute to the adolescent's ability or inability to adjust to and manage their diabetes. In summary, an adolescent who has low self-esteem, poor social skills, and adverse environmental stress, will more than likely not be able to manage their diabetes as well as one who has good coping and communication skills, an internal locus of control, and a positive image of themselves.

Weight Issues and Eating Disorders

Sociologists have long recognized the importance of the cultural norms of society. The current Western idolization of thinness has had an impact on fashion, sale of merchandise for fitness and individual lifestyles, and particularly on our focus on weight and increase in eating disorders.

In a general study of children who did not have diabetes (Felts, 1996) of the 10,000 students in grades 9-12, 25% believed that they were too fat. This supports the cultural norm that extends back to the 1970s in which it was noted that 34.6% of the females and 14.4% of the males felt that they were too fat (Stuart & Jacobson, 1979). A later study noted that 75% of adolescent females felt they were fat compared with 25% of the males (Fodor & Thai, 1984). This concern with thinness seems to impact females more frequently and may play an important role in the proposed differences between diabetes care of females and males. Since females report concern over being fat at a substantially higher rate than males, they may be more concerned about their appearance, and/or be more likely to be involved in disordered eating behaviors than their male counterparts. This is tied in with issues of excessive weight, disordered eating behaviors, diet, insulin manipulation, social pressures (particularly on females), and the consequences of not treating diabetes as mentioned below.

To have diabetes and live in a culture that is focused on being thin presents a significant dilemma. Several studies have noted that adolescent and young adult patients, both males and females, with IDDM weighed significantly more than their non-diabetic peers in control groups even in the first year of the introduction of insulin therapy (Peveler, Fairburn, Boller, & Dunger, 1992; Steel, Lloyd, Young, & MacIntyre, 1992; Steel, Young, Lloyd, & MacIntyre, 1989). Butler and Wing (1995) pointed out that the tendency to gain weight may compel those with IDDM to lose the excessive weight as this would probably be an undesirable side-effect of diabetes treatment. Once again, since adolescence is a time in which the teenager is determining their identity by exploring different roles, being thin can become an important component in the search for a sense of self.

Artificially controlling insulin through adjusting injections is certainly not the same as having one's body control the levels and may contribute to weight gains. Being overweight in a society focused on being thin may lead those with diabetes to feel inadequate or lead to eating disorders or disordered eating behaviors. Marcus and Wing (1990) have noted that from 1960 through 1980, there was a noteworthy number of reports of adolescents with diabetes who later developed eating disorders (anorexia and bulimia). The research is controversial about whether adolescents with diabetes have a higher rate of eating disorders than the general public. Some larger, older studies using self-reports noted that there was a higher rate while smaller, newer studies using the Eating Disorder Examination instrument have noted that there is no difference in the rate of eating disorders between teens with diabetes and control groups without diabetes (Birk & Spencer, 1989; Fairburn, Peveler, Davies, Mann, & Mayou, 1991; Hudson, Wentworth, & Pope, 1985; La Greca, Schwarz, & Satin, 1987; Peveler, Fairburn, Boller, & Dunger, 1992; Powers, Malone, Coovert, & Schulman, 1990; Rodin, Craven, Littlefield, Murray, & Daneman, 1991; Rodin, Johnson, Garfinkel, & Kenshole, 1986; Stacin, Link & Reuter, 1989; Striegel-Moore, Nicholson, & Tamborlane, 1992).

It is unclear what all the factors are that contribute to disordered eating behaviors, but studies by Rosmark, Berne, Holmgren, Lago, Renholm, and Sohlberg (1986) and Rodin, Johnson, Garfinkel, Daneman, and Kenshole (1986) indicated that IDDM may accelerate the onset of eating disorders in adolescent females. This may result in part because of the strict regimen that is required to maintain metabolic control, such as rigid diet control and preoccupation with weight. Diet control and a focus on weight combined with the ready availability of insulin manipulation may serve as a weight control mechanism. The medical situation becomes more difficult to manage when diabetes is compounded with an eating disorder as insulin is generally administered to the adolescent based on determining the need as indicated by blood sugar. Blood sugars will fluctuate rapidly with binging and purging behaviors. For those with diabetes who develop eating disorders, the condition may be a result of the combination of a restricted diet, feelings of deprivation leading to binge eating, and weight gains that result from excessive insulin (Marcus & Wing, 1990; Peveler, Fairburn, Boller, & Dunger, 1992; Polivy & Herman, 1985; Polivy, Herman, Olmsted, & Jazwinski, 1984; Stacin, Linke, & Reuter, 1989; Steel, Lloyd, Young, & MacIntyre, 1989; Steel, Young, Lloyd, & MacIntyre, 1989).

Individuals with IDDM and eating disorders may manipulate their weight by their use or nonuse of insulin. Although it is dangerous, reducing or eliminating insulin causes a person with IDDM to lose weight rapidly. Insulin is the key that opens up the cell to allow the calories inside to be used by the cell for energy. Calories pass through the body quickly when insulin is not present, glucose accumulates in the blood, is filtered through the kidneys, and the calories are spilled out in the urine (Butler & Wing, 1995).

In many women, particularly young women, the goal to be attractive and thin is taken to extremes. Tolmach and Scheer (1984) found that women are more willing to physically and mentally harm themselves to achieve weight control than men. Furthermore, Stancin (1989) found that women with IDDM often use insulin restrictions for weight control. In a study of 93 women with IDDM 18-30 years old, 40% reported reducing insulin as a method of weight control (La Greca, Schwartz,& Satin, 1987).

Weight control is an issue for both adolescents with and without diabetes. Thinness is a cultural norm in the United States. Although it is unclear whether there are greater numbers of teens with diabetes who have eating disorders than those without diabetes, it is clear that preoccupation with thinness for the adolescent with diabetes can and often does result in serious health risks. Inappropriate manipulation of diet and/or insulin can lead to hospitalization or coma or even death. More females than males are likely to risk their health to get and remain thin. This is probably due to different social norms for male and females. The quest for thinness with a disregard for health may be one of the most difficult problems to address and change for the adolescent who has diabetes. Issues, such as, societal expectations, peer pressures, and identity development must be addressed in order to change behavior and free a members of this group from concerns over their weight and allow them to focus on appropriate diabetes care.

Family Culture and Dynamics

It is important to acknowledge the role of the family, particularly the parents (Bowman, 1985) in the care of diabetes for the adolescent. The family stress levels, parental support and involvement, parenting style, conflict, mother and daughter relationships, and responsibility all play a role in the care that the teen receives.

Stress

Stress in a family often has a negative impact on the adolescent with diabetes. In a study with 12 adolescents ages 15 to 18 years old, Mengel, Lawler, Volk, Viviani, Dees, and Davis (1992) found that increased parental stress resulted in poorer diabetic control. An already stressed family may be more susceptible to the impact of diabetes. One study indicated that those families from lower socioeconomic levels with marital difficulties had a higher prevalence of psychiatric difficulties following the diagnosis of diabetes in the family (Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock, & Crouse-Novak, 1985). However, several studies indicated that after the initial adjustment, adolescents and families are generally able to cope adequately with diabetes care (Jacobson, 1996; Jacobson, Hauser, Wolfsdorf, Houlihan, Milley, Herskowitz, Wertlieb, & Watt, 1987; Kovacs, Brents, Steinberg, Paulauskas, & Reid, 1986; Kovacs, Finkelstein, Feinberg, Krous-Novak, Paulauskas, & Pollock, 1985).

Parental Support and Involvement

Parental support and involvement is another important factor in managing diabetes care. The skill level of the families as they cope with diabetes is important. Diabetes demands much attention to detail and having a schedule can assist in incorporating the procedures needed to control diabetes. In a longitudinal study of 9 to 16 year olds who had been diagnosed as having diabetes within the previous year (Wertlieb, Hauser, & Jacobson, 1988), the children with diabetes who perceived their families as being highly organized demonstrated fewer behavioral problems. A family with structure was perceived by the adolescent to have assisted the teen in their adjustment to diabetes. Parental support was directly related to adherence to diabetic care and the younger the subjects the more compliant because the parental support was greater as shown in a study by Hanson, Henggeler, and Burghen (1987) of 104 adolescents. It is logical that parents would be more involved in diabetes care with younger children than older ones as it is easier for parents to influence the environment and care of younger adolescents. Older adolescents are encouraged to take an active role in their diabetes care. Furthermore, older adolescents may rebel against parental involvement, and parents may have less control of older adolescents.

Parenting Style and Conflict Resolution

Parenting style and the way conflict is resolved in the family also impacts how the adolescent with diabetes controls their disease. Historically work has been conducted on problems in families who have a child with diabetes with particular attention to the importance of family functioning and conflict (Baker, Minuchin, & Rosman, 1974; Minuchin, Baker, Rosman, Liebman, Milman, & Todd, 1975). Marrero, Lau, Golden, Kershnar, and Myers (1982) noted that adolescents (13 to 18 year olds - 16 males and 24 females) with IDDM who perceived their parents as dominating and controlling had poorer metabolic control while those who perceived that they had a positive relationship with both of their parents and that both of their parents supported their autonomy, demonstrated good metabolic control.

Better family cohesion and ability to resolve conflict were correlated with good control at one and four years post IDDM onset for adolescents (Hauser, Jacobson, Lavori, Wolsdorf, Herskowitz, Milley, Bliss, Wertlieb, & Stein, 1990). It is very clear that parenting style, including positive conflict resolution and support for autonomy aids adolescents in managing their disease. Perhaps diabetes care becomes a tool in the power struggles between adolescents who strive for autonomy and parents who strive for control. Those families with positive communication patterns who allow their teenagers age-appropriate freedom may avoid power struggles in general and the use of diabetes as a weapon.

Mother and Daughter Relationships

The type of relationship between mothers and adolescent daughters seems to be critical. There have been several studies looking at this relationship and how it impacts both the mother and daughter. One study by Bobrow and AvRuskin (1985) involved a diverse group of 50 adolescent females (12 to 17 years old - 17 White Protestant, 15 White Catholic, 8 Jewish, 7 African Americans of various religious backgrounds, and 3 Mexican American Catholics with incomes ranging from $7,000 on public assistance to $60,000 a year). The study indicated that there was a great deal of conflict demonstrated between mothers and their daughters who had diabetes. The less adherent the adolescent to a diabetic regimen, the more negatively charged was the mother-daughter relationship. Mothers who frequently challenged daughters with unacceptable behavior or lying often escalated the conflict, and this usually resulted in the adolescent withdrawing. It is unclear whether the mothers and their daughters would have conflictual relationships without the diabetes, and whether the conflicts were the sole result of noncompliance to diabetes care.

In another study of the mother daughter relationship, compliance was better in younger girls if the mothers had taken an active role in concrete tasks and supervising the management of the treatment in a study of 12 to 17 year olds by Bobrow, Ruskin and Siller (1985). Hauenstein, Marvin, Snyder, and Clarke (1989) studied 25 mothers of children who had diabetes. The mothers felt that they were less attached to the child with diabetes, perceived themselves as less healthy, and received less support from husbands than did a control group of 21 mothers of children without a chronic illness

The research on the mother-daughter relationship indicates the possibility of a circular relationship in which the diabetes negatively impacts the adolescent. This may accelerate the conflict between mothers and daughters. Because mothers are generally caregivers of the children in families, the teenage girl may feel rejected and feel that they have lost a part of their support system by the increase in conflict with their mother.

Although there are many difficulties in adjusting to diabetes, the situation is not hopeless. A few studies demonstrated that adolescents who have difficulties coping with the adjustment of IDDM respond well when taught in a group setting how to respond to problems surrounding diabetes (Bernbaum, Albert, & Brusca, 1989; Marrero Myers, Golden, West, Kershnar, & Lau, 1982; Padgett, Mumford, Hynes, & Carter, 1988). This highlights the importance of including the family in the adjustment to diabetes care.

Responsibility

An important component of diabetes care is that of parental responsibility. Again, in our society, it is generally accepted that a parent is responsible for the care, of their minor child which includes medical care (Mc Cormick & Brooks-Gunn, 1989). Many adolescents are able to actively participate in their own diabetes care and parents are usually encouraged to allow them to take charge of the components which they are able to conduct, such as giving injections. There is no standard to base a shift from parent-to adolescent-orchestrated care. A child may be able to administer their own shots at 10 to 12 years of age (or even younger) but not be willing to take over this task until they are well into their teen years. The complexities of the responsibility for care are reflected in the fact that adolescents, parents, and professionals are unable to agree on what is an age appropriate shift in the responsibility. In a study of 490 subjects by Wysocki, Meingold, Abrams, Barnard, Clarke, Bellando, and Bourgeois (1992), both parents and adolescents (3-19 years old) rated lower levels of abilities to care for diabetes than the professionals. Professionals believed that the children were capable of managing certain skills at older ages than the parents. These skills included the ability to anticipate and plan for hyperglycemia, adjusting insulin appropriately, checking for ketones in the urine, checking the quality of insulin, recording test results, and dietary planning at restaurants.

In a review of the clinical and empirical evidence, Follansbee (1989) concluded that age alone is not the best indicator of when to give the adolescent the responsibility of self-care. Some of the other factors that seem to impact good management or compliance are knowledge, cognitive complexity, locus of control, organization of family, actual performance by the adolescent, perceptions of the adolescent about what he/she feels willing to do, as well as how well these perceptions match the caregiver's perception of what the adolescent is able to do. Follansbee concludes that all these factors must be taken into account when trying to accomplish successful management or compliance. It may be difficult for parents to assess all of these factors to determine the correct age for allowing the teen to manage their own diabetes. Moreover, teenage behavior is often erratic. Testing blood sugar may be a skill that is easily learned by an adolescent yet not conducted as social engagements take precedence.

The physical ability to conduct diabetes care is also complex. To demonstrate the difficulties, in observations of 6 to 18 year olds (Epstein, Coburn, Becker, Drash, & Siminero, 1980) it was found that 54% of their judgments about urine testing alone were in error. Urine testing is a fairly simple test involving dipping a color coded chemical strip into urine and matching the color to those on the test strips bottle. This is used to determine if ketones are present and determines the need for treatment, particularly in an ill child. In the range of procedures that help to maintain diabetes control, the urine test is fairly simple. This study suggests that more complicated procedures may also be conducted incorrectly and interfere with diabetes care.

Physical ability to conduct the procedures and emotional maturity to accept the responsibility are both part of the process of diabetes care. Common sense tells us that an older adolescent may be more capable of caring for diabetes than one who is younger. While one study indicates that transferring older adolescents (16-18 year olds) to an adult focused diabetes program does not appear to negatively impact their diabetes control (Orr, Fineberg, & Grey, 1996), a study of even older individuals (Dunnings, 1995) who were 17-34 years old noted that of the 59 young adults who responded to a questionnaire, only 68% tested their blood at least once a day and 12% never tested their blood. It is impossible to maintain adequate control over diabetes with blood tests only accumulated once a day or not at all. Blood sugars fluctuate throughout the day and multiple tests over the course of 24 hours allows the medical provider or family to alter insulin to accommodate the adolescent's ever-changing needs. The very important Diabetes Control and Complications Trial (DCCT) conducted on many adult subjects to determine whether more frequent attention to diabetes made a difference, confirmed that more increased daily testing and frequent injections contributed to much better diabetes management (DCCT, 1988).

Daneman (1991) recommends that parents remain involved with their teenager's diabetes care.

> Finally, I advise you to remain involved in your child's diabetes care and know what is going on both as you transfer control and afterwards. Just because parents decrease their role in diabetes management does not mean that the youngster automatically assumes it (p. 66).

For all adolescents, the impact of family interactions is significant. For the adolescent with diabetes these interactions can alter their health status from being relatively healthy to being in a hospital, having long-term complications, or even dying. The above studies have shown that stress, parental support, parental involvement, parenting style and conflict, and the relationship between mother and daughter all have an effect on how well teens can manage their disease and how compliant they are in following the steps to manage their disease.

Responsibility for the management of the disease is a family decision that significantly impacts teens with diabetes. Although there are no "hard and fast" rules about ages that teens should take responsibility for the management of their disease, there are guidelines that indicated by the studies. They are: 1) maturity levels are more important than age levels; 2) responsibility should be shifted gradually from the parent to the teen; 3) some parental involvement even into the late teens can be beneficial. The qualitative data portion of this research project is designed to provide more information on responsibility.

Because diabetes is such a complicated disease that requires constant adjustment, monitoring, and administration of management techniques, family involvement and participation is critical. Disorganized families with poor parenting skills who are unable to accept responsibility for their children's behavior usually leads to disastrous results for the adolescent with diabetes.

Community Context

Access to Medical Care

To further clarify an attempt to understand the management of diabetes in adolescents, the medical care must be considered. Access to health care and compliance to medical regimes are two very relevant features. Access to health care is listed as one of the most important aspects of care by Bowman (1985). Health care resources are not always available because of a lack of insurance or geographic access. Some families do not have health insurance to provide for the health needs of their family members. Many health insurance policies have copays or do not cover medical supplies. Likewise, although a family may qualify for Children's Special Health Care Services (a form of Medicaid for children with chronic illnesses), this is income dependent and often mandates that families pay a portion of the costs of the insurance. Because of the high cost of test strips for HBGMs, families may pay of out-of-pocket costs for these strips. Despite access to health care through insurance, the geographic availability can be another barrier. For example, in rural areas there may not be a clinic where diabetes specialty care is available nor other teens who have diabetes to provide peer support.

Access to health care is an important community and societal issue that has not been resolved. Resources may not be available to provide specialized diabetes care to all of the teens affected. Individual worthiness to have available health care is also being challenged as we decide who will be included and eliminated in health care coverage when there are limited resources. Our society is in the process of making decisions about this as we shift to a system that utilizes managed health care. The debate continues as to whether health care is a right or a privilege. The next few years may be an era of great change for those with chronic illness as decisions are made that impact their ability to access and afford care.

Compliance

Compliance has several components. There are individual issues, family issues, health provider issues and societal issues. This section of the paper, although dealing briefly with the individual and family issues, focuses on the health care issues of the health provider and the society in the area of compliance.

Amiel, Sherwin, Simonson, Lauritano, and Tamborlane (1986) suggest that insulin resistance occurs during puberty in both normal children and children with diabetes and the combined effects of puberty and diabetes on insulin action may help explain the difficulty some adolescents have in maintaining control of diabetes. However, it is difficult to determine whether true insulin resistance is the case, as those adolescents who become ill from a lack of insulin may be rebelling by omitting insulin. In a study conducted by Golden, Herrold, and Orr (1985) with 44 pediatric patients with diabetes, 70% of the children who were in recurrent diabetic ketoacidosis (RDKA) were shown to not be taking their insulin, and two thirds of the group admitted to not taking it. Compliance improved significantly when another family member took over the responsibility of giving the insulin.

In some studies, these noncompliant teens would have appeared to be insulin resistant. Modern laboratory testing may allow for a more timely determination of the difference between noncompliance and insulin resistance, and future studies may allow health care providers to alter diabetes regimens or confront noncompliant teens.

Noncompliance presents as a significant social dilemma to health care providers. Studies of adults indicate that those with chronic illnesses often do not fully follow the advice of their physicians (Stewart & Sullivan, 1982). To continue to treat a rebellious teen who refuses to adhere to medical recommendations may imply an acceptance of their negative behaviors and later may set the stage for a community reaction as the patient suffers long-term, permanent physical effects, such as kidney failure. There may also be a societal reaction as the government must absorb the extensive cost of treating the individual who may be permanently disabled from what may be deemed their own decisions of neglecting their diabetes care. Society may decide that they are unwilling to support individuals who knowingly damage their bodies.

Conversely, there is a moral and ethical dilemma with discharging a noncompliant adolescent from health care. First, there may be no alternative health care available within the geographic region. Second, as stated previously, our society generally holds parents responsible for their minor child's care, including health maintenance. When a parent refuses to take over the diabetes management for a minor who is unable or unwilling, the child is then punished through rejection and a lack of medical care when the parent may actually be the legally and morally responsible party.

The health care provider is then in a precarious position which may place them in the interface between the family and society. The health care provider may be deemed by society to be responsible for the overall health management of the adolescents with diabetes, particularly in this era of managed care. Struggling with societal and parental demands may place an unrealistic burden on the health care provider and certainly add complexities to policy decisions, such as allowing a physician the ability to discharge noncompliant patients.

It is important to note that the issue of compliance has strong ethical and moral implications, particularly for the adolescent. Patient self-determination plays a role in that it is often left up to the patient or family to decide on the degree of willingness to comply with medical recommendations. Furthermore, quality of life versus adherence to medical regimens should be included in a decision. While compliance is an important feature of this discussion, time does not permit for the topic to be given adequate justice.

In the qualitative portion of this study, questions 11 and 14 address compliance. It is difficult to assess whether teens skip insulin doses or avoid blood testing. However, wherever possible, it is important to assess how often this happens and the possible motivations for the nonconformance.

Access to health care through ability to pay and geographic location are important factors in a community and in society to provide for its members. This influences the economic climate as well as the included moral and ethical dilemmas. This is complicated by the compliance or noncompliance of patients that receive medical care within the community. These features impact decisions that are made regarding providing health care and must be considered in future policy decisions.

Summary

Review of the literature seems to indicate:

1. Adolescence is a time to resolve the conflict between autonomy and dependency and is often a time of physical and emotional crisis.
2. Peer pressure plays an important role in the development of the teen.
3. Adolescent girls are more concerned about appearance than adolescent boys.
4. Newly diagnosed IDDM adolescents often are depressed.
5. Teens who have good communication and conflict resolution skills are usually better able to control their diabetes.
6. Weight issues are of major concern to teens particularly female teens, and insulin can cause weight gains. Whereas, misuse of insulin can cause weight loss.
7. Stress in a family often has negative impacts on the adolescent with diabetes.
8. Parental support and involvement are important factors in managing diabetes
9. Teens who see their parents as supportive manage their disease better than teens who do not see their parents as supportive.

10. The mother-daughter relationship is important in the management of the disease.
11. The age when the teen can take responsibility for managing the disease varies from individual to individual.
12. Geographic and financial access to medical care impacts how well the teen is able to manage the disease.
13. When adolescents do not manage their disease there is a significant impact on the individual, in the family, by the health providers and in the society.

In this literature review, it is evident that many factors impact the adolescent with diabetes. A summary of the literature referenced in this document is found in Appendix A.

CHAPTER III

RESEARCH DESIGN

Introduction

This chapter explains the research design. In this exploratory project, there were many complex facets and the research included quantitative and qualitative components. They will be presented separately for ease of understanding the information. The quantitative data were drawn from an intense chart review which compared male and female adolescents by age grouping. The qualitative data were drawn from interviews of adolescents who were shown to be in poor and good control of their diabetes, according to the quantitative data. These interviews were undertaken to compare and contrast their situation for a better understanding of what was taking place in their lives in hopes that information would be derived that might contribute to better diabetic control. Included here are the speculations underlying this research in the form of the hypotheses and the use of the literature for a framework.

Quantitative Data

Quantitative data were gathered to determine differences in adolescents and provide a framework to explore what was occurring in regards to diabetic control among the teens.

Recording of Data

Charts were reviewed to determine demographic data on each subject. This included their birth date, gender, type of insurance, date of diagnosis, geographic location, whether they had another illness, and each glyco result that they obtained. The dependent variable, indicated in Table 1 as "Total Glyco" involved averaging the subjects glycos and utilizing this mean as a judge of degree of control over their diabetes.

Table 1-Example of Recording of Quantitative Data

SUB	DATE OF BIRTH	INSUR	DATE OF DX	OTHER ILLNESS	ZIP CODE.	GLYCOS				TOT AL GLY CO
F1-18	11-10-78	P	1992	0	48912	9.2	10.9			10.1

All information was taken from 1996 data. Table 1 shows the format in which the information was recorded for the first female subject who was 18 years old. First, subjects were recorded by gender ("F" or "M"), and an identifying number was assigned to each subject within the age and gender category. Second, their date of birth was noted to confirm their age and to compare it to the date of diagnosis. Third, insurance was noted as "P" or "N" to indicate that subject paid ("P") some portion of the costs of attending the clinic or did not pay ("N") any costs but all the costs were billed to their insurance. Fourth, the date of diagnosis was recorded and those who were diagnosed with diabetes less than one year were eliminated from the study as explained in a subsequent section on subject exclusion. Fifth, those with other chronic illnesses were noted, and they were also eliminated from the study. The reasons for this elimination are also discussed more fully in the section on "Subject Inclusion and Exclusion". Sixth, zip codes were recorded that indicated geographic location of the subjects. This was done to determine whether subjects had to commute long distances to receive medical care. Seventh, individual glycos were recorded to assist in determining an average and to see if there were patterns. Finally, an average glyco was calculated and used extensively in this research.

Glycohemoglobins

State of the art in medicine currently determines overall control of diabetes through the use of a single blood test drawn in a laboratory for a percentage of blood sugar. This gives an average that represents a level of control for a period of approximately 2 to 3 months (Anderson, et al, 1994; The DCCT Research Group, 1988). This blood sample is processed by a laboratory test called the glycohemoglobin (glyco) or glycosylated hemoglobin. This test is generally conducted on patients at the time of their clinic appointments. The test is also indicated every 2 to 4 months to continuously monitor control of diabetes. The nondiabetic range (4.8% to 7.8%) shows that the patient has good control of their diabetes. At the MSU Pediatric Diabetes Clinic, medical staff consider any number below 10% as an indication of acceptable control of diabetes. The higher the number, the worse the control. Patients whose percentages are 13% or higher are considered to be in danger of diabetic ketoacidosis (in which sugar cannot be utilized by the body and the patient risks going into a coma) and long-term diabetic complications such as eye disease, nerve damage, and kidney failure (B.E. Wilson, personal communication, November 4, 1996).

Subject Inclusion and Exclusion

The subject pool for the quantitative data was identified from a list generated by the MSU Pediatric Diabetes Clinic that included patients between the ages of 13 and 18 years old who have diabetes. All subjects who had another chronic illness were eliminated from the research as it was too difficult to determine whether the other illness impacted the control of blood sugars. For instance, cystic fibrosis can induce diabetes in some patients and control could be severely complicated by this disease.

Subjects with diabetes less than one year were not included. Research indicates that there may be adjustment problems within the first year, such as depression difficulties. To avoid confounding the data. subjects were only included if they had diabetes more than one year (Kovacs, 1979).

The final n was 93. Since the outcome measure involved utilizing an average of glycos, any patient without at least two glycos was eliminated from any of the analyses that utilized averages, for a sample size of 77.

Collecting Data

After receiving human subject approval, and based on the list of patients from the MSU Pediatric Diabetes Clinic, each chart was retrieved and the demographic information and glyco results of 1996 were recorded as previously noted. Several factors made this process complicated. Charts were not always well organized and many had to be reviewed from front to back to assure obtaining all relevant information. Information was sometimes recorded in different places. For example, not all face sheets at the front of the chart contained information on insurance so the MSU Clinical Center computer system was utilized for current insurance carriers. Since glycos were the outcome measure used to indicate control, it was especially important to obtain all information on glycos. Some patients obtained glycos at other locations because they were mandated by their insurance to utilize the carriers' facilities. Results of these glycos were often not found in the Laboratory Tests section of the charts and extensive medical dictations were read to facilitate the attainment of some glycos as staff contacted the laboratory, and physicians recorded the glycos at the subsequent clinic appointment or dictations. Finally, some laboratories conduct their glyco tests differently than the MSU Clinical Center laboratory and they obtained different norms for the results. Alternative laboratory results had to be converted to MSU Clinical Center Laboratory standards by medical staff to assure comparisons of similar data on glycos. All of these situations made the collection of quantitative data extremely time consuming.

Qualitative Data

In the study of adolescents with diabetes, it is important to understand the functioning of the child within the environment. Despite the enormous complexities of adolescents with chronic illnesses and their families, qualitative research is an important part of looking at individual functioning, performing within a family, the impact of the community, and in this case, the intricacies of health care. Qualitative research is helpful in understanding information that is presented in words or pictures instead of mere numbers (Daily, 1992). Many people and things impact teens in their attempt to manage the diabetes, and it is difficult to assess what was taking place with only quantitative information. This section explains the gathering of the qualitative data.

As noted earlier, the adolescents' glycos were compared to determine differences in males and females by age to show level of control of diabetes. Based on the results of the information, subjects were recruited who were in poor control (above 12%) and good control (less than 10%) to assist in determining differences in their lives (See "Subject Inclusion and Exclusion" for details).

Recording and Coding of Data

The qualitative data were coded to facilitate an understanding of the adolescent's responses. Coding is a form of analysis (Miles & Huberman, 1994). Two forms of coding analyses were used in the qualitative portion of this study. First, questions were individually analyzed by breaking down responses into keywords. Categories were developed for each question to cluster responses into similar classifications. Each subject's response was then placed into one of the categories to assess patterns of responses. Included in this clustering was a notation of poor or good control to maintain an understanding of the responses for both groups.

Table 2-Sample of the Chart for Recording Qualitative Data

QUESTION 3 - In your experience, what is the most difficult part of having diabetes?			
NO SWEETS	**NOT BEING LIKE OTHERS**	**DIFFICULTY IN SPORTS**	**TIME FOR DIABETES CARE**

Table 2 demonstrates the method used for recording the qualitative data. It shows that four basic responses were given to "Question 3". This format also allowed for noting the number of subjects who responded each way.

The second type of coding involved analyzing subject's overall responses by themes. For example, those subjects who utilized keywords that expressed a sense of responsibility were noted by the use of the word responsibility or a word or phrase that denoted the concept. These data are presented in Chapter 4.

Subject Inclusion and Exclusion

The letters found in Appendix B or C were mailed or given to subjects whose glycos were below 10% and above 12% to recruit for interviews. It was decided that a small difference, such as that between 9.9% and 10.2%, might not be a good reflection of a segregation of good and poor control. It was hoped that by selecting those on more extremes of the continuum of good and poor control, this would allow for a reflection of significant differences in factors that might impact control of diabetes in the subjects. It was determined that a subgroup of 10 subjects (5 in good control and 5 in poor control) would be recruited from the 77 who were analyzed in the quantitative section. This offered more rich data on the lives of the subjects.

Participation of subjects for the qualitative portion was voluntary. Flyers were mailed or given to subject's parents (Appendix B or C) which offered an incentive of $10.00 for each subject's participation. Interestingly, after the flyers were distributed, those who initially responded to the request for voluntary participation were mostly males (5 of 6) and in good control (5 of 6). Those in poor control (3 of 4) and more females (3 of 4) responded to a second distribution of the same flyer. Although the chart review in the quantitative portion was based on the total population of adolescents at the MSU Pediatric Diabetes Clinic, the subjects in the qualitative study were totally voluntary in response to the flyer that was distributed to their parents. Recruitment was limited to a 60 minute drive from the MSU Clinical Center in order to facilitate obtaining the information needed. All subjects beyond this geographic range were not sent flyers to solicit their input. This only eliminated 13 subjects. The qualitative data were then generated from a somewhat selective group of adolescents as it did not include those a significant distance from the MSU Clinical Center (which might have eliminated some rural subjects), did not include those in moderately poor or good control of their diabetes (with glycos in the 10.1 to 11.9 range), and obviously was self-selective as subjects chose to participate. This might mean that subjects with extreme behaviors, such as those who never test blood sugar numbers did not volunteer and, were not well represented in this sample.

At the beginning of the interview, subjects were assured that the results of their answers would not be shared with the staff at the MSU Pediatric Diabetes Clinic nor parents so that they would feel free to provide accurate information. This was done while the researcher reviewed the permission form (Appendix D) with the parent and adolescent. The form was read to the adolescent and parent prior to the interview and both signatures were obtained except for the case of the 18 year old subject in which the parental signature was not necessary. Therefore, all precautions were taken to assure confidentiality so that subjects would feel free to be as honest as possible.

The possibility of an ethical dilemma for the health care professional may present in this type of research when an adolescent answers questions and reveals they are participating in behaviors that are harmful. For example, a teen may report that they frequently miss shots of insulin which will lead to severe health problems. Ideally, research will be conducted which allows subjects to give honest responses to questions to allow the researcher to obtain accurate information. In the case of imminent danger, when the subject reveals information that requires immediate intervention, such as the case of suicidal behavior, the researcher is obligated to seek help for the adolescent so that they do not die. However, this situation did not arise in this interview process. In this research, physicians are well aware of the level of control of the diabetes as demonstrated in the glycos of the subjects, and the staff at the MSU Pediatric Diabetes Clinic are involved in on-going contact with the parents to assist with better diabetes control.

Interviews

Interviews were conducted in the clinic and in the home of those who volunteered. These took about 60 minutes to complete. Subjects were asked questions from a preselected group of open-ended questions (Appendix E). All interviews were audio tape recorded. Based on the results of the chart review and quantitative analysis, interviews were organized to assist in determining what was taking place in the lives of the adolescents. Open-ended questions were generally designed to obtain information from the subjects about various aspects of their lives but directly and indirectly related to diabetes.

Questions 1 and 2 were asked to determine when the patient was diagnosed and what they remembered about the situation. These were designed to get the subjects talking and comfortable with the researcher. Questions 3 through 7 were about caring for the diabetes and were used to determine who played a role in caring for the diabetes and the patient's understanding of the disease and its control. Numbers 8 through 13 were intended to obtain information on difficulties that might play a role in control, such as the most difficult part of having diabetes. Because of literature reference to problems with anorexia and bulimia in adolescents with diabetes, questions 14 through 16 were used to assess possibilities of eating disorder behavior. Question 17 was included to determine restrictions relative to diabetes. Because exercise is important for anyone with diabetes, question 18 was used to ascertain activity levels. The fifth section, questions 19 through 23, was asked to establish those who play a role in the support of the research subjects. Questions 24 to 26 were included as medical care is so critical to diabetes management. It was presumed that if patients had other health care providers or particularly positive or negative feelings toward medical care, this might influence their willingness to seek help from physicians or medical staff. Finally, questions 27 to 29 were especially designed to allow the adolescents to speak openly about their situation and provide general information on their lifestyles and struggles in the care of diabetes. At the end of the interview, all subjects were offered an opportunity to include any other information that might not have been addressed in the questions.

In response to the flyer, parents left messages on a telephone that had an answering machine. They were called back based on their responses and interviews were set up at mutually agreed upon times. Interestingly, most of the subjects (8 of 10) expressed gratitude at having an opportunity to express their views at the time of the interviews. They reported pleasure at being allowed to tell their story and while they gladly accepted the $10.00 stipend, they expressed enjoyment of the process.

Hypotheses

This research is an exploratory project that involved reviewing patient charts to assess differences and similarities in adolescents with diabetes and conducting interviews to enhance the results. There were five hypotheses that were developed at the time of this study. These hypotheses are given in Chapter I. These hypotheses involved speculations on gender and age differences in controlling diabetes, included length of time subjects had diabetes, and number of glycos obtained during the year.

Summary

The chart review provided information on the tangible aspects of diabetes care for the adolescent. This information was enhanced by the use of open-ended questions to determine more intangible aspects, such as the adolescent's struggles, perspectives, and supports. The analyses of the data are presented in Chapter 4. Chapter 5 provides a synthesis through a discussion of the results and how these are relate not only to existing research provided in the literature but also how they might guide future research.

CHAPTER IV

RESULTS

Introduction

This research project stemmed from a combination of an intensive literature search that revealed a lack of research on adolescents with diabetes comparing gender and age issues, combined with clinical experience in which adolescents as a developmental group appeared to have had a more difficult time controlling their diabetes than younger or older patients. This experience included staff's belief, at the MSU Pediatric Diabetes Clinic, that adolescent females were having a more difficult time than males. This led to the research presented here, which was comprised of a chart review with statistical analysis and interviews, as an exploratory method of determining what was taking place with adolescents attempting to control their diabetes.

Quantitative Analysis

The statistical analysis involved looking at the data from several views. Emphasis was on viewing the glycos as an outcome measure of control of diabetes. As previously reported, the use of the glyco is well substantiated in medicine as a gauge of the level of control of diabetes (Anderson, Anderson, & Glanze, 1994; The DCCT Research Group, 1988, 1996). The glyco is a blood test that is conducted by drawing blood from the arm in a laboratory and the results show a percentage of sugar in the blood over a two to three month period of time. This test is unlike the blood test that is conducted through the finger poke done by the adolescent themselves which measures a current blood sugar number and is analyzed by a portable blood sugar machine about the size of a calculator (a glucometer). The blood sugar obtained by the adolescent is important for adjusting current insulin doses. However, the glyco is an accurate test of what is taking place over a two to three month time period (Tate, Clements & Walters, 1992) and was used in this study as the measure of control of diabetes. Ideally, a patient will have three to four glycos a year. As previously noted, the national guidelines, which are used at the MSU Pediatric Diabetes Clinic, are a range of 4.8% to 7.8%. This is the laboratory standard which indicates that the adolescent with diabetes is controlling their diabetes so well that it is as if they did not have diabetes and will be less likely to suffer diabetic complication (Anderson, Anderson & Glanze, 1994; The DCCT Research Group, 1995).

The first few tables depict demographic information about the research sample who are adolescents with diabetes attending the MSU Pediatric Diabetes Clinic. Subsequent Tables address the statistical analysis.

Demographics

All subjects with any other chronic illness were eliminated. This included diabetes induced by cystic fibrosis and other conditions such as congenital adrenal hyperplasia and hypothyroidism as any such disease impacted the endocrine system and may complicate the control of diabetes. Furthermore, it was determined that any other chronic illness might provide excessive strain on a family system and complicate the quantitative data. Patients with Type II diabetes were also eliminated, despite being adolescents, as this is considered a separate disease from IDDM and was not suitable for a comparison with this group. Table 3 represents the sample of adolescents with diabetes included in this study who attended the clinic

Table 3-Subjects by Gender Categories

	FREQUENCY	PERCENTAGE
FEMALES	49	52.7
MALES	44	47.3
	93	

in 1996. All of the quantitative information was obtained from charts of patients who attend the MSU Pediatric Diabetes Clinic. The ratio of females to males is almost equal for a total of n=93, and the mean age is 15.35 years old.

Table 4-Subjects by Age and Gender Categories

SUBJECTS BY AGE	FEMALES		MALES		TOTAL	
	n	%	n	%	n	%
13 YEARS	10	20.0	10	22.7	20	21.5
14 YEARS	7	14.3	6	13.6	13	14.0
15 YEARS	9	18.4	7	15.9	16	17.2
16 YEARS	9	18.4	8	18.1	17	18.3
17 YEARS	7	14.3	5	11.3	12	12.9
18 YEARS	7	14.3	8	18.1	15	16.1
TOTAL	49	52.7	44	47.3	93	100.0

The adolescents in this study ranged from 13 to 18 years old. There were 44 males (47.3%) and 49 females (52.7%) in each age group, and this is reflected in Table 4. Again the ratio of females to males is fairly consistent throughout the age groups.

Table 5 notes the frequency of subjects who receive average glycos. It is interesting that less than 25% (23.4%) have glycos that represented ideal control. Ideal control in this study is defined as glycos below 10% as are utilized in national guidelines (Anderson, et al., 1994; The DCCT Research Group 1995, 1996; Tate, Clements, & Walters, 1992) . Individuals with Type I diabetes who kept their glycos under 10% are less likely to develop complications related to poor control, such as kidney disease, kidney failure, eye disease, and blindness (DCCT Research Group, 1995, 1996). Of further interest is that Table 5 also shows more than 25% (27.3%) of the adolescents in this population had glycos over 13% which indicates very poor control. The higher the glyco percent, the less the diabetes is in control and the more likely the adolescent is to suffer complications from their diabetes in the near future. Several studies note the use of the national criteria used to denote ideal control. Ideal control in this study is defined as glycos below 10% as are utilized in national guidelines (Anderson, et al., 1994; The DCCT Research Group, 1995; 1996; Tate, Clements, & Walters, 1992) . Individuals with Type I diabetes who can kept their glycos under 10% are less likely to develop long term complications related to poor control, as mentioned above.

Table 5-Frequency of Subjects' Glyco Range

GLYCOS PERCENT	FREQUENCY	CUMULATIVE PERCENT
7.0-7.9	1	1.3
8.0-8.9	3	5.2
9.0-9.9	14	23.4
10.0-10.9	18	46.8
11.0-11.9	13	63.6
12.0-12.9	7	72.7
13.0-13.9	9	84.4
14.0-14.9	5	90.9
15.0-15.9	3	94.8
16.0-16.9	2	97.4
17.0-17.9	1	98.7
19.0-19.9	1	100.0

Poor control in this study is defined as glyco averages over 10% while very poor control is an average glyco over 13%. The lack of good overall control is also seen in the mean glyco level of the subjects in this study which is 11.14% with a standard deviation of .262.

Table 6 depicts the categories that the adolescents were placed into to divide them into early (13 to 14 year olds), middle (15 to 16 year olds), and late (17 to 18 year olds). These categories were used in the analysis for a comparison to see if one age group was in better or worse control and are used extensively in this study.

In Table 6, 77 (83%) of the original 93 subjects in this study represent those adolescents who received at least two glycos. The glyco levels for each of the 77 subjects were averaged and used in the following comparisons and statistical analysis. The 16 (17.2%) who were not included were those who only received one glyco and were unable to have averages for comparisons. Most of the statistical tests that were done were based on averages.

Table 6 Grouping of Male and Female Subjects by Age

	MALES		FEMALES		TOTAL	
	n	%	n	%	n	%
EARLY (13-14)	14	35	13	35	27	35
MIDDLE (15-16)	14	35	16	43.2	30	39
LATE (17-18)	12	30	8	21.6	20	26
	40	100	37		77	

Table 7 provides information on the number of glyco tests for the subjects in this study, which covers 1996. As is noted, 16 (17.2%) adolescents only received one glyco test. Only 40 (43%) of the 93 adolescents received what was considered an adequate amount of testing, which was three to four glycos a year (Anderson, et al., 1994; The DCCT Research Group, 1995; 1996; Tate, Clements, & Walters, 1992). Compliance in receiving glycos was especially poor with less than half of these subgroups obtaining adequate medical care for their diabetes.

Table 7-Number of Glycos in 1996 Per Subject

NUMBER OF TESTS	FREQUENCY	PERCENT
1	16	17.2
2	37	39.8
3	35	37.6
4	5	5.4
	93	100

Table 8 and Table 9 represent information on this population in which adolescents received glycos that were over 10% and at or over 13%. These charts were separated into genders as it was speculated in the hypotheses that there may be a gender difference. The data are presented by age categories as this was part of the exploratory nature of this research. The numbers represent raw data and percentages of individual subjects who received at least one glyco over the given amounts. The 10% cut-off was given to show those who received glycos over the 10% acceptable standard that was presented earlier and clearly noted in the literature as an indicator of good control. The 13% was given at the MSU Pediatric Diabetes Clinic to note extremely poor control. As glycos go higher, the diabetes was in more poor control and the risk of diabetic complications increased. These two tables (8 and 9) indicated the number of times the adolescent had at least one glyco over the acceptable range in both poor control (10%) and extremely poor

Table 8-Females With At Least One Glyco Above 10.0% and Above 12.9%

SUBJECTS BY AGE	TOTAL SUBJECTS	GLYCOS 10% TO 12.9%		GLYCOS OVER 12.9%	
		n	%	n	%
13 YEARS OLD	10	5	50.0	3	30.0
14 YEARS OLD	7	1	14.3	2	28.6
15 YEARS OLD	9	1	11.0	4	44.4
16 YEARS OLD	9	4	44.4	4	44.4
17 YEARS OLD	7	1	14.3	4	57.1
18 YEARS OLD	7	3	42.9	3	42.9
TOTAL FEMALES	49	15	30.6	20	40.8

control (13%). For females, 15 of the 49 (30.6%) were in poor control, while for the males 20 of 43 (46.5%) are in poor control. The far end of the continuum was represented by 20 of the 49 (40.8%) females in extremely poor control and 13 of the 43 (30.2%) of males in extremely poor control. Of particular interest is that among 16 to 18 year old females and males, 71.4% of this population had glycos over 10%.

Table 9-Males With At Least One Glyco Above 10.0% and Above 12.9%

SUBJECTS BY AGE	TOTAL SUBJECTS	GLYCOS 10% TO 12.9%		GLYCOS OVER 12.9%	
		n	%	n	%
13 YEARS OLD	10	4	40.0	3	30
14 YEARS OLD	5	2	40.0	1	20
15 YEARS OLD	7	4	57.0	1	14.2
16 YEARS OLD	8	5	62.5	2	25
17 YEARS OLD	5	1	20.0	3	60
18 YEARS OLD	8	4	50.0	3	37.5
TOTAL MALES	43	20	46.5	13	30.2

Also playing a role in the adolescent's ability to receive adequate medical care may have been the availability of insurance. It was speculated that this was particularly critical information in this instance as it may cost

$150.00 or more for the patient to be seen by the physician in the subspecialty clinic for a comprehensive examination. It was presumed that if families had to pay for medical services, that it may deter them from obtaining medical care. Most of this population had adequate insurance coverage to pay all medical expenses (71%) and only incurred travel expenses for all of their clinic appointments. This included not paying any copays or deductibles. The remaining 27 (29%) paid at least a copay or deductible with no patients paying the entire cost of the visit (i.e., no insurance).

Data Analysis

The next section begins the information on the analysis of the data. There are several different methods that were utilized to assist in understanding this population in relation to their control of diabetes. An ANOVA, several chi-squares and multiple regression analysis utilized to analyze the data.

Table 10 shows the Analysis of Variance (ANOVA) with a 2 x 3 factorial design to test the main effects of gender, age, and the interaction of gender and age. The effects for the interaction of age and gender were not significant [$F_{(2,71)} = .55$, p=.581]. These results show that the main effect for gender was not significant [$F_{(1,71)} = 1.08$, p=.302] indicating that there were no statistically significant differences between males and females in their glyco levels. The main effects of the three age groups (early, middle, late) was not significant [$F_{(2,71)} = 1.52$, p=.226]. These nonsignificant results show no detectable differences in this population for age, gender and/or interactive effects based on an ANOVA.

Table 10-ANOVA for Effects of Gender, Age, and Interaction of Gender by Age

VARIABLES	SUM OF SQUARES	DF	MEAN SQUARE	F	SIG. OF F
GENDER	5.763	1	5.763	1.080	.302
AGE	16.189	2	8.094	1.517	.226
GENDER X AGE	5.835	2	2.917	.547	.581

In the Chi-Square tests of Tables 11 and 12, the continuous outcome of the average glyco was categorized into dichotomous variables of 10% or less, and greater than 10%. These categories were utilized to determine if the distribution of males and females was the same in both glyco level categories. As indicated in Table 11, although there is a higher percent of females with glycos over 10%, there is no significant difference between males and females in the glyco outcomes [$\chi^2_{(1)}$=.19, p=.659]. Although it is not statistically significant, it is interesting to note that about two-thirds of the adolescents have glyco levels greater than 10%, which again indicates that overall their diabetes is not in good control.

Table 11-Chi-Square Results of Glycos for Males and Females

GLYCOS	FEMALE	MALE	TOTAL
EQUAL TO OR LESS THAN 10%	13 35.1%	16 40.0%	29 37.7%
GREATER THAN 10%	24 64.9%	24 60.0%	48 62.3%
COLUMN TOTALS	37 48.1%	40 51.9%	77 100.%

$\chi^2_{(1)}$=.19, p=.659

Table 12 utilizes Chi-Square to analyze the age categories (early, middle, and late) and it reveals that there was an apparent similarity in the percent of low glycos as the age group varied from early to late adolescents. The same pattern existed for those with greater than 10% glycos. The distribution was the same so there is no statistical significance for Chi-Square for three age categories with glycos equal to or less than 10% and greater than 10% [$\chi^2_{(2)}$ = .91, p=.63].

Table 12-Chi-Square Result of Glycos for Age Categories

GLYCOS	EARLY (13-14)	MIDDLE (15-16)	LATE (17-18)	TOTALS
EQUAL TO OR LESS THAN 10%	10 37.0%	13 43.3%	6 30.0%	29 37.7%
GREATER THAN 10%	17 63.0%	17 56.7%	14 70.0%	48 62.3%
TOTALS	27 35.1%	30 39.0%	20 26.0%	77 100%

$\chi^2_{(2)} = .91$, p=.63

Part of this research involved looking at whether there was a relationship between patients who must pay for services at the clinic and the number of glycos that they obtained. It was speculated that cost may prohibit receiving adequate medical care. Although it was not statistically significant [$\chi^2_{(1)}$=.94, p=.33], Table 13 showed interesting results. While those who had to pay any money for services represented less than one-half (29.9%) of the subjects, they only represented 25% of those who obtained three glycos versus those who did not pay any fee who more frequently received three glycos (75%).

Table 13-Chi-Square Results of Payment and Nonpayment of Services by Number of Glycos

PAYMENT	2 GLYCOS	3 GLYCOS	TOTALS
NO PAYMENT	24 64.9%	30 75.0%	54 70.1%
MUST PAY FOR SERVICES	13 35.1%	10 25.0%	23 29.9%
TOTALS	37 48.1%	40 51.9%	77 100%

$\chi^2_{(1)}$=.94, p=.33

The final analysis, a Multiple Regression Analysis (Table 14), examined the effects of the independent variables of gender, age, length of time having diabetes, and the number of glycos conducted, and whether the insurance paid or not on the average glyco level. Although the females had higher glycos, this independent variable did not demonstrate any statistical significance (β_1 = –.10 t= –.84, p =.40) For the age variable, the t test showed no statistical effect on glyco levels (β_2 = -.08, t= -.64, p = .52). Length of time with diabetes was an independent variable that also showed no statistical significance (β_3 = - .00, t = -.02, p = .99). The number of glyco tests were not statistically significant (β_4 = .-.03. t = -.23, p = .82). Finally, whether the patient had to pay for some portion of the services or the insurance paid the entire bill was not statistically significant (β_5 = -.08, t = -.64. p =.53).

Table 14-Multiple Regression Analysis with Five Variables: Gender by Age by Length of Time with Diabetes by Number of Glycos by Payment

VARIABLES	BETA	STD ERROR BETA	t	SIGN. t
GENDER	-.101	.550	-.842	.403
AGE	.078	.171	.635	.527
LONG	.002	.072	.018	.986
NUMBER	-.028	.462	-.230	.819
INSURANCE	-.076	.598	-.640	.524

Findings by Hypothesis

This research project was an exploratory project that began with assumptions about adolescents with diabetes. Each hypothesis was addressed separately and related to the results of the findings from this research.

Hypothesis #1:

There will be differences between control of diabetes for adolescent males and females, based on the results of their glycohemoglobins.

Quantitative Results:

There was no statistically significant difference found in control of diabetes between males and females. An ANOVA and Chi-Square tests were utilized to obtain this information. These results were complicated by the fact that, with one exception, 18 year old females only had one glyco done a year, and those females were generally in poor to extremely poor control. While there were no specific gender differences, it is clear that the adolescents in this population were generally in poor control.

Hypothesis #2:

There will be differences in age categories (i.e. early, middle, and late adolescents) of males and females in control of diabetes based on the results of their glycohemoglobins.

Quantitative Results:

Two separate Chi-Square tests were used and both did not demonstrate any statistically significant differences for gender or age.

Hypothesis #3

There will be differences in the interactive effects between age and gender, based on the results of the glycohemoglobins.

Quantitative Results:

Gender, age and an interaction of gender and age did not reveal any statistically significant differences on an ANOVA.

Hypothesis #4:

There will be differences in gender for dichotomous glycohemoglobin levels of equal to and less than 10%, or greater than 10%.

Quantitative Results:

A Chi-Square tests was conducted which revealed no statistically significant differences in glycohemoglobins for dichotomous levels of equal to and less than 10% versus greater than 10%.

Hypothesis #5:

There will be differences in gender or age categories for independent variables of gender, age, length of time with diabetes, number of glycohemoglobins obtained, and whether patients paid for services.

Quantitative Results:

A Multiple Regression Analysis indicated no statistically significant differences in glycohemoglobins for subjects for gender, age, length of time with diabetes, and number of glycos obtained and payment for services. Despite these results, again, an anomaly presented when the recorded data showed that the 18 year old females in this study were generally only obtaining one glyco test per year and that those single tests were generally in the range of poor control to extremely poor control.

Qualitative Analysis

The qualitative analysis was designed to enhance the information in the quantitative research. Interviews of subjects were conducted to determine factors that played a role in control of diabetes, considering both internal and external influences. Five subjects in good control and five subjects in poor control of various ages and from both genders were interviewed. Interviews were used to obtain a broad perspective from different ages and genders. The first method of analysis consisted of utilizing a form (Table 2) that allowed for systematically coding and clustering answers to compare and contrast by category of the answers. The second method involved looking for themes in each subjects set of responses.

For the first portion, each question was recorded on a separate sheet of paper. Table 2 shows how answers were recorded by topic and negative or positive aspects of the topic.

Each question was put into this format of a table with answer categories. These were derived from the same categories used to cluster similar interview questions and are presented topically in this section. This assisted in determining not only categories of answers but also the number of subjects who responded similarly. There was no limit placed on categories. If each subject had answered the question differently, there would have been

10 columns for the answers. However, this was not utilized as most subjects shared similar answers with others. This method resulted in the following analysis. A good deal of relevant information was gleaned from this process and is presented in categories for clarity.

Care of Diabetes

- All subjects, regardless of level of control, conducted their own blood sugar tests, shots, and drawing of insulin with the exception of one 13 year old female (in good control) who had her mother's input on drawing insulin and occasionally giving shots, and one 13 year old male (also in good control) who discussed insulin adjustment with his mother.

Insulin Adjustment

- Of those who adjusted their insulin only when they had a clinic appointment at three or four month intervals, all three subjects (one male and two females) were in poor to extremely poor control.
- The most frequently used pattern of insulin adjustment was that subjects (two in poor control and three in good control) changed their overall dose infrequently (less than once a month) but supplemented their regular insulin when their blood sugars were

high. They gave the supplement because their current blood sugar number was too high.

- One subject (in good control) changed insulin based on patterns of highs or lows as is the standard recommendation for ideal control by the staff of the MSU Pediatric Diabetes Clinic.
- Although in good control, one subject (male) changed his dose constantly (at least once a day) based on his current blood sugars, which was contrary to medical advice.

Control Levels

- Eight of the 10 subjects knew their level of control or glyco level.
- Two subjects, in poor control of their diabetes (one male and one female), were totally inaccurate about their control based on the glyco averages, reporting that they had good control when they were in extremely poor control. This information was always reviewed with the patient and parent at the clinic visits so they should have been aware of their glyco levels.

Most Difficult Part of Having Diabetes

- The two most common difficult components of having diabetes were reported as abstaining from sugary foods (three subjects); being different from peers (two subjects), and a combination answer of abstaining from sugary foods and being different from peers (two subjects) for a total of seven of the 10 subjects (70%).

- The remaining three subjects reported that the most difficult part of having diabetes was the time it took for diabetes care.

Missing Insulin

Most subjects reported missing shots with six of 10 (60%) only missing a shot occasionally. One subject (in good control) reported never missing a shot. Predictably, the three subjects who most frequently missed shots (one or more missed shots a month) were those in the poorest control.

Inaccurate Reporting of Blood Sugar Numbers

- All of the subjects who were interviewed reported that they had lied at some time about their blood sugar results with five citing the reason as their desire to eat sugary foods and five giving a reason to avoid conflicts with parents or doctors.

Worry

- All but two subjects (those in extremely poor control) worried about having diabetes with their main concern respectively given as going blind, developing kidney disease and heart problems, and one subject included not being able to get pregnant or have a healthy child.

Body Image

- All 10 subjects reported being satisfied with their looks.
- Five of the 10 subjects expressed satisfaction with their weight but these were all males.
- All four of the females expressed some level of desire to lose weight.
- One male expressed a desire to lose 10 pounds but this was so that he could participate in a sports activity that required him to fit in a specific weight category, not because of a concern for his appearance.
- All four of the females and the one male who wanted to lose weight reported that they would not become involved in disordered eating behaviors (i.e., purging or restricting) as they were concerned about the effects of this behavior on their blood sugar numbers.

Restrictions

- Four of the 10 subjects reported that diabetes did not restrict their lives in any way.
- Four of the 10 subjects reported that it only placed restrictions on their ability to eat sugary foods.

- Two reported missing out on some normal childhood functions (a sleepover and an overnight field trip) because no one was able to monitor the diabetes in case of a low blood sugar reaction.
- One of the 10 subjects (a male in good control) wanted to reduce his weight to participate in sports but felt restricted from doing so because he was afraid of being unable to control his low blood sugars and passing out during the sports activity. Prior to his diabetes he had participated in extreme methods of weight loss, including completely restricting food for 24 hours and longer and excessive exercise.

The responses pointed out that six of the ten subjects did not feel restricted by diabetes except for their inability to eat sugary foods.

Support

- Mothers were listed as the most influential support person by six of the 10 subjects (60%)

Two of the 10 subjects listed their mothers and fathers as equal in supporting and assisting them despite the fact that one of these subjects had a father who was not in the home because of a divorce.

Themes That Presented in the Interviews

The second portion of the qualitative analysis involved viewing the overall responses of the subjects for themes. This was particularly important when comparing those in good and poor control and is presented below.

Good Control

Regardless of age or gender, those adolescents in good control had distinct themes of positive coping strategies and attitudes as follows:

Personal Responsibility

- "It is a very big responsibility and needs to be taken care of very carefully."
- "There will be things that they want to do and they'll want to be able to help themselves and not be reliant on Mom and Dad all the time, or the Guardian. They need to be self-reliant. By the time they are driving, they should be in total control before that."
- "I've done a hands-on demonstration and have people go up and test. It shows them what is going on. I explain it to my teachers - what is going on - so they would know."

Acceptance of the Disease

- "It's serious, control is important, not just in the future, but every day, and I feel good when I have good control."

- "That it is okay. It's not the end of the world. You have to deal with it. You have to balance what you eat and take good care of yourself."

Positive Attitude

- "It really doesn't affect your life other than the fact that your blood sugar doesn't stay normal."
- "That it's not bad. You just have to get used to it and take care of yourself."

Poor Control

Conversely, the subjects in poor control expressed several problems in coping with the diabetes, as noted in the following areas:

Inappropriate/Inaccurate Understanding of their Condition

- "To me, honestly, they said it was bad, but to me it means good, because my lst one was 17.7." (A 17 year old female with extremely high glycos reported her recent glyco of 15 to be acceptable as she had had higher (i.e. worse) results in the past.)

"It's okay. I don't have many problems. My control is okay." (An 18 year old male reported his glycos in good control when his glyco average was 12.5% for 1996.)

Missing Insulin Shots

- "I miss about 2 or 3 shots a month. It's okay because I just take more insulin the next day because my blood sugar is too high."
- "Just a couple of weeks ago I skipped a shot. I was doing something - I think bowling or something."
- "I wouldn't take them [shots] at night."

Not Worried About Consequences/Diabetic Complications

- "I don't really worry about it. I'm pretty active and eat pretty well."

The following example was from one adolescent in extremely poor control that depicts her painful dilemma at having diabetes during the teen years.

- "You just want to be accepted. You don't care about the consequences at that time."

The qualitative data were drawn from a small subgroup (n=10) of the overall subjects in this study (n=93). A picture can be drawn of the subgroup based on their responses with some responses shared by the entire group, and others limited to those in poor or good control. These are summarized below.

It is clear from the interview that these adolescents were, for the most part, managing their own diabetes. This included adjusting insulin doses either well or poorly. Despite medical recommendations to the contrary, most subjects gave themselves supplemental shots of regular insulin, based on their current blood sugar. Subjects viewed diabetes as making them different from their peers (especially in that they could not eat the junk food that their friends consumed) and felt that diabetes care took too much time from their schedules. All of the teens had felt compelled to lie about blood sugar numbers to be able to eat sweets or avoid arguments with parents or doctors. The subjects generally did not report much of a restriction on their lives because of the diseases except for wanting to consume sugary foods like their peers were doing. Mothers were listed as the most important support for teens.

Those in poor control were the most likely to miss shots of insulin. Those in the worst control had inaccurate information on their level of control (which might have been due to a lack of education or from being in denial about the severity of their condition) and did not worry about their diabetes as opposed to those in good or somewhat poor control who worried about diabetic complications. This lack of concern may support the possibility of the most potentially serious cases being in denial about their condition.

All of the females expressed some level of desire to lose weight, which is consistent with the existing literature that is presented in this document that reports that females are more concerned about weight than males. However, all of the females and one male expressing a desire to lose weight stated that they would not become involved in disordered eating as it would make diabetes too difficult to control. This is inconsistent with the previously reported research that shows extensive eating disordered behavior and issues with adolescents with diabetes. It actually suggests that having diabetes, in some instances, may work to prevent or reduce the chances of a teen with diabetes developing an eating disorder.

Those teens in good control reported themes of responsibility and a positive acceptance of their diabetes.

This synopsis offers a comparison of some of the major issues that were expressed by the subjects who were interviewed.

Summary

This exploratory research project revealed several interesting features of this population of adolescents with diabetes through quantitative and qualitative analysis. First, the subjects were generally in poor control of their diabetes. Second, that despite no statistically significant differences in quantitative data, interviews indicated that younger adolescents may have more parental input into insulin management. Third, most subjects were not managing their insulin appropriately despite being left to mange it by themselves. This includes feeling compelled to lie about blood sugar results at some point in time. Themes of responsibility, acceptance of the disease, and a positive attitude were demonstrated in word phrases used by those subjects in good control while some older adolescents in extremely poor control had an inadequate understanding of their level of control or were perhaps in denial of the lack of control, as presented in the glyco results. Discussion of the possible ramifications of these findings are presented in the next section.

CHAPTER V

DISCUSSION

Introduction

This section will involve synthesizing the results of this exploratory research along with the current literature and relevant issues. The material will be presented beginning with the individual, broadening to the family, and ending with issues of the social context. Since this exploratory project was designed to serve as a framework for research on adolescents with diabetes, possibilities for the direction of future research will be outlined.

Psychosocial Factors

Issues in the lives of adolescents with diabetes highlighted in the literature were depression, stress, communication styles, conflict resolution, social competence, self-esteem, peer pressure, and eating disorders. These issues will be addressed in this section.

None of the adolescents in this project expressed depression, nor did the researcher observe any signs of depression, such as a flat affect. Kovacs (1979) wrote about depression in adolescents who were newly diagnosed with diabetes and attributed this depression to the grieving process. Potential subjects in this study were purposely eliminated if they did not have the disease longer than one year. The motivation for this selection process was not to eliminate those with depression, but to study those who had become somewhat adjusted to the changes that diabetes brought to their lives. If Kovacs' information is accurate, subjects in this study were consistent in not presenting with depression as they would likely be past the grieving stage and depression.

Poor diabetes control is associated in studies with an external locus of control combined with a low self-esteem (Grossman, 1987), and poor social interactions and competence combined with stress (Hanson, Henggeler, & Burghen, 1987). Perhaps those teens with difficulties with social interactions are deterred from discussing their difficulties, obtaining information, and reviewing other options. This may be reflected in this study by those subjects in poor control who had an inaccurate understanding of the results of their glycos.

Similarly, the quest for esteem appeared to be an important goal in those in poor control in that acceptance by peers was expressed in the qualitative interviews as more important than the consequences of the cost of not taking care of the diabetes as discussed in the qualitative analysis in Chapter 4. Although it may be difficult for adults to believe, the threat of death or severe illness from diabetes complications may not be as important to some adolescents in this culture as the threat of not being accepted by their peers. This would fit the picture of an adolescent with a poor self-esteem and perhaps poor social skills. The literature notes that younger adolescents are more vulnerable to peer pressure than older adolescents (Berndt, 1989; Bixenstine, DeCorte, & Bixenstine, 1976; Collins, & Thomas, 1972). Younger adolescents (or those less mature) may be more willing to be involved in deviant behaviors. Our Western culture often involves strong peer pressure to conform and may include adolescent norms of lying or stealing (Thornburg, 1982). All of the subjects in the interviews reported that they had lied about their blood sugar numbers at some time. Diabetes makes an adolescent different from their peers. The fact that the quantitative data shows that 62.3% of all of the adolescents in this study were not in control of their diabetes speaks to the question of the role of acceptance. By inaccurately reporting low blood sugar numbers, adolescents with diabetes can engage in a common practice of eating junk food with peers. Parents and health care providers would be wise to work with the adolescent to either plan for consuming sugary foods or acceptable alternatives that the teenager can share with their peers to make them similar instead of different.

A study of adolescents in good control of their diabetes showed that they demonstrated positive communication skills and an ability to resolve conflicts effectively (Wysocki, 1993). This may be a reflection of a maturity level that is not always consistent with an adolescent's chronological age. Subjects in this study in good control expressed themes of acceptance and responsibility in the interviews. Incorporation of the cause and effect relationship is an important developmental task for the adolescent (Inhelder & Piaget, 1958; Piaget, 1970, 1972). This mature outlook toward diabetes is also seen in the compliance of those in good control who reported that they infrequently or never missed a shot of insulin. Good communications and conflict resolution skills may be a reflection of developmental maturity that appears to be consistent with acceptance of the disease.

The difficulties with eating disorders are addressed as a separate psychosocial issue because of its prevalence in Western society and the potential for the great impact that it may have on the lives of adolescents with diabetes. Interviews revealed that half of the subjects in the study felt that they should lose some weight. This is consistent with studies of adolescents reporting that they were too fat (Fodor & Thai, 1984; Stuart & Jacobson, 1979). Although interviews involved a small sample size, this report of overweight may be influenced by the fact that teenagers with diabetes tend to weigh more than their peers without diabetes (Peveler, Fairburn, Boller & Dunger, 1992; Steel, Lloyd, Young & MacIntyre, 1992; Steel, Young, Lloyd, & MacIntyre, 1989). A study by Butler and Wing (1995) expressed concern that increased weights in teenagers with diabetes may compel them to participate in disordered eating. However, all of the subjects denied any involvement in disordered eating behaviors (i.e. purging and severely restricting calories). Five of the 10 (two in poor control and three in good control) explained that they would not engage in these behaviors because it would make diabetes management too complicated and they risked hypoglycemic episodes. Since all the subjects openly admitted to lying about blood sugar numbers, it would seem logical that they would be truthful about whether they were involved in eating disorders. These responses suggest that diabetes may actually be an inhibitor to eating disorders as opposed to a motivator. This interesting finding obviously needs further extensive research.

Although the data is not statistically significant, it appears that there may be trends with the most important being that most of the subjects were in poor control. When viewing poor control (10%-12.9%) versus extremely poor control (13%+) based on subjects single glyco values, females had a lower percent of subjects in poor control while males had a higher percent in poor control. When looking at those in extremely poor control, the data is reversed in that females had a higher percent of subjects in this category compared with males. Eighteen year old females in this study had a glaring lack of glycos with only six of seven obtaining glyco more than one glyco and all of these single values were in poor to extremely poor control. With older females lacking adequate testing and females showing a higher percentage of single values in extremely poor control, this study indicated a need to conduct further research to determine if there are gender differences as well as to investigate reasons for the potential differences.

Aside from information on eating disorders, this study was fairly consistent with the current literature. Since adolescents generally live in families and must function within the context of the home environment, the next section will draw together aspects of this research that relate the information to the family functioning.

Family

Research has shown that poorer diabetic control was found in adolescents whose parents had high levels of stress and who were domineering and controlling (Marrero, Lau, Golden, Kershnar, & Myers, 1982; Mengel Lawler, Volk, Viviani, Dees, & David, 1992). Another study showed that families who are stressed with economic difficulties and martial problems face more psychiatric difficulties following a teenager's diagnosis of diabetes (Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock, & Crouse-Novak, 1985). Conversely, organized families with strong parental support offered a medium for good control of diabetes for adolescents (Hanson, Henggeler, & Burghen, 1987; Wertlieb, Hauser, & Jacobson, 1988). The importance of a well functioning family was evident in the literature.

Although one study cited adolescent females with diabetes having a great deal of conflict with their mothers, the qualitative results of this research indicated that mothers played an important role in diabetes management. Mother's were listed as the most influential person for the adolescent by 6 of the 10 subjects with 2 of the 10 listing their mother and father as equal supports. (This included a divorced couple in which the father lived at a different residence.)

Since the adolescent must function within the family context each day, it is not surprising that the family influences diabetes control in either a positive or negative fashion. One of the difficulties that faces the adolescents is that they are frequently working their way to becoming more autonomous. Diabetes may force a parent to focus on a teenager and fail to let them pass through stages of independence that would be a normal part of the developmental process. This may cause conflicts that would otherwise be avoided. This research reveals that all of the subjects in the qualitative portion had lied at some time about blood sugar tests. This situation may undermine a parent's confidence in their teenager and again force them to place excessive restrictions on the adolescent. There is no easy answer to this dilemma as diabetes can be a life-threatening condition if not treated properly. Missing insulin shots and failing to test blood sugars and adjust insulin can lead to severe health problems or even death. Parents of adolescents with diabetes may need to interfere in the process of autonomy by intervening in the life of the teen who is not taking care of their diabetes. This situation certainly impacts development and provides speculation for extensive future research.

Community

Finally, the adolescent with diabetes lives and functions within their community. They must have access to health care for treatment of the diabetes (Bowman, 1985). Geographic proximity and insurance to cover the expenses are important considerations in obtaining control of diabetes. The subjects in this study were generally located within a one hour drive of the facility so there was no ability to compare them with rural patients.

Quantitative data was gathered on insurance to determine if cost was prohibitive. Most of the subjects (71%) who attended the MSU Pediatric Diabetes Clinic had more than adequate insurance coverage which meant that their families did not pay any money (not even a copay or deductible) for services. It is expensive to see a subspecialist and cost may be a deterrent to those who do not qualify for Medicaid and do not have insurance. Certainly information on a more economically deprived area in which subjects had little to no insurance, would assist in comparisons.

Summary

Individual, family, and community issues all impact the adolescent with diabetes. Taking into account all of the physical, emotional, psychological, familial, supportive, conflictual, educational, and service aspects is a complex process. Each component must be broken down and then put back into the picture to provide a broad understanding.

Future Research

Future research is an essential component in studying the teenager with diabetes. This section will address general and specific aspects of the research and offer some direction for other projects.

General Issues for Future Research

It is noteworthy that all 10 of the interviewed adolescents report satisfaction with their looks. This may indicate that despite their level of control, the subjects self-selected because they had a fairly good self-esteem as it would take some confidence to feel that one's answers were worthwhile. Furthermore, this researcher would caution the reader to avoid inferring extensively from this information because of the sample size as this is an exploratory study. Future research would ideally involve large samples and include a random selection of subjects for qualitative purposes.

Perhaps the most interesting information that came from this study is that the adolescents in this population have an overall difficult time controlling their diabetes with 62.3% of the subjects having glycos over 10%. More important, 27.3% have glycos over 13%, which represents extremely poor control. This has several possible implications, including that the staff of the MSU Pediatric Diabetes Clinic are not adequately assisting the adolescents in care; that the adolescents themselves are not attending to their diabetes on a daily basis; that parents or caregivers are not adequately monitoring the diabetes; that it is too difficult for most people to control Type I diabetes with the current technology that is available; or that the social, emotional and psychological challenges of adolescence make diabetes care difficult. While this research is exploratory and further research needs to sort out more of these factors, this author believes that it is a combination of the factors listed above that interferes with diabetes control. Just as important, information needs to be researched on effective interventions to improve control.

This research was focused on adolescents with diabetes. The fact that 62.3% of the subjects were not in control of their diabetes is interesting, however, it is difficult to truly understand this percentage without comparing it with younger children and adults. If one of these groups has a rate of poor control that is higher, then the subjects in this study may be considered in better control. Future research should include comparisons across the entire life span and also include longitudinal information to see if there is a pattern of increased problems with control of diabetes during the adolescent years.

Another issue is that of compliance. Care must be taken in equating compliance with control. Subjects may be totally compliant with medical regimens and yet not be in control of their diabetes. Again, more research is needed to determine if compliance is directly correlated with control in adolescents. Subjects' admissions of lying about blood sugar tests makes speculations about the adolescent's ability to be compliant open to criticism. Research in this area may include randomly calling subjects across the country at different times of the day to confirm compliance through most recent care of diabetes.

Finally, it is possible that the lack of statistically significant results is an artifact of the small sample size. Future research should expand to include different geographical locations and a larger sample size to increase the evidence of degree of control.

Specific Issues of Future Research

An area that is notable is that the older females (18 years old) were generally only obtaining one glyco test per year (six of seven subjects). This may indicate that there is a problem with this subgroup. Furthermore, all six subjects had glycos over 10%. The lack of averages to include most of the 18 year old females in the late adolescent group may have influenced the results of the statistical testing, particularly since this group had poor single glyco results. It would be interesting to know why these females only attended the clinic one time in 1996 since this group failed to respond to a request for interview subjects. Furthermore, the tendency for females in this study to have a higher percentage of single value glycos in extremely poor control combined with the lack of data on 18 year old females indicates a need to investigate gender and age differences more thoroughly.

Information on eating disorders in this research is not consistent with the literature for national averages of the general population nor concerns for increases in eating disorders for adolescents with diabetes because of tendencies to higher weights. Future research is needed to determine if there are eating disorder behaviors among teenagers with diabetes. Binging and purging and severely restricting calories are particularly dangerous to teens with diabetes as they could rapidly become hypoglycemic and go into a coma. This aspect of diabetes care deserves extensive national research as this culture idolizes thinness.

Since the subjects in this study were generally located close to the clinic, it would be important for future studies to include adolescents in rural areas. Perhaps these teens are being treated by a pediatrician or family practice doctor who may know little about diabetes. A comparison of rural and urban subjects would be helpful in determining whether control was influenced by geographic location as related to receiving health care.

Three important areas that were outside the parameters of this study were socioeconomic status, intellectual abilities, and family functioning. These factors are all very relevant to diabetes care. For example, unidentified costs may prohibit some families from attending the clinic more regularly and parents or adolescents who are intellectually challenged may not understand the instructions for diabetes care. These and many other factors need to be examined in future research.

Policy, Research, and Clinical Implications

Policy, research and clinical practice implications may be derived from this project and are highlighted in this section by looking at issues of technology and methods of direct health and mental health care.

This was an exploratory project designed to determine what was taking place with adolescents who attend the MSU Pediatric Diabetes Clinic. While no gender or age differences were found to be statistically significant, a larger sample within the United States may reveal differences and therefore a more extensive research project would be helpful. This could be accomplished by networking with established pediatric subspecialty clinics throughout the United States.

It is economically advantageous for national funds to be provided for diabetes research. Teenagers with diabetes are often seen by subspecialists in an effort to treat or prevent some of the complications that are potential side-effects of diabetes, including renal failure (Brink, 1987). This clinical setting allows researchers access to adolescents with diabetes and the research may assist in preventing complications that will lead to disablement (such as renal failure). Adequate health care may allow individuals with diabetes to remain productive members of society and avoid the federal costs associated with their health care and support if they become disabled. The societal cost of their disablement may also be reflected in the family's decreased productivity through such possibilities as one parent giving up employment to take care of the disabled child (Rosenberg, 1991).

Technology in health care is changing rapidly. This research highlights some areas that the population of adolescents desire for improved diabetes control. This includes providing a way for them to eat junk food with their peers and decreasing time attending to diabetes care. Health care dollars for advances in technology must include consideration for cost effectiveness for extending life as well as improving quality of life (Muller, 1991). For example, one teen suggested a blood sugar monitoring device that was like a watch worn on the wrist that continually monitored blood sugar numbers. While this would be an ideal method of assisting teens with diabetes, it may not be financially advantageous to pursue this avenue until technology has improved enough to make it cost effective to have extremely small computers for this purpose. It would be important to balance health care dollars, technology, and methods of assisting adolescents with diabetes.

Finally, health and mental health professionals may be assisted through some of the findings in this project. One of the most important findings, within the quantitative analysis, was that the adolescents in this study were generally not in good control of their diabetes. Since this is exploratory research, more data is needed to determine whether the adolescents in the United States have a similar rate of poor control. Should national averages be similarly poor, clinicians may need to develop specific programs designed to address the difficulties that adolescents have in diabetes control. This may include additional education, support, and counseling designed with the adolescent's specific issues, such as the need for autonomy. This may take the form of individual, group, and family counseling, regular visits by a social worker to the home, closer monitoring through intensive clinic appointments, networking by staff with the teen's school to exchange information and increased monitoring, and allowing more freedom for autonomy when the adolescent achieves better management of their disease.

Social workers on multidisciplinary teams can play crucial roles in assisting adolescents in poor control. For example, case management services may assist the patient and family by coordinating services for more frequent clinic appointments and glyco testing, and monitoring blood sugar testing and administering of insulin through phone contacts. Services may also include conducting individual and family counseling, facilitating support groups, and conveying diabetes education to provide information and clarify misconceptions for improved care. These types of interventions will need to be researched to determine whether they are effective in improving the glyco levels of adolescents who receive the services.

Summary

This exploratory research project was designed to offer information about adolescents with diabetes in the areas of gender, age, health care expenses, length of time with diabetes, glyco tests, and factors that impact their lives. The results serve as a basis for future research. Obviously there is much room for research in studying the adolescent with diabetes. As technology changes, diabetes care may become more conducive to the teenage lifestyle, but for now, despite advances in the last few years, the care of diabetes is complex. It is hoped that this research will lead to more in-depth studies as well as interventions that are designed to assist adolescents with diabetes.

APPENDIX A

APPENDIX A

Review of Literature Summary

Research Topic	**Subtopic**	**Result**	**Date**	**Researchers**
Sociology	Role	Defines sick role	1951	Parsons
		Health Belief Model	1979	Rosenstock & Kirscht
			1988	Kirscht
		Depersonalization of individual by medical institutions	1984	Kallen
		Patients taking a more active role in health care	1978	Marston
		Quality of life issues	1989	Freeman & Levine
	Adolescence	Task of adolescence is resolution of conflict between autonomy & dependency	1984	Kallen
		Undervaluing adolescence as a transitional period	1995	Young, Anderson & Steinbrecher
		Teens have mental health needs	1993	Takanishi
		Establishing identity	1968	Erikson
		Male & female roles	1996	Tischler
		Formal Operations; Stages in Adolescence	1958	Inhelder & Piaget
			1970	Piaget
			1972	Piaget
		Peer pressure	1990	Savin-Williams & Berndt
		Peer pressure more important for younger adolescents	1979	Berndt
			1976	Bixenstine, DeCorte, & Bixenstine
			1972	Collins & Thomas
		Older adolescents spend more time with peers	1984	Csikszentmihalyi & Larson
		Issues for adolescents such as body image, eating disorders, violence, sex, drugs, etc.	1986	Blumstein, Cohen, Roth, &Visher
			1986	Kandel, Davies, Karus, &Yamaguchi,
			1980	Kandel
			1988	Violato, & Holden
			1986	Boskind-White, & White

Research Topic	Subtopic	Result	Date	Researchers
Sociology cont'd.	Adolescence	Older adolescents spend more time with peers Issues for adolescents such as body image, eating disorders, violence, sex, drugs, etc.	1983 1986	Lucas, Beard, Kranz, & Kurland Strober
Diabetes-discovery & treatment	Nos. of children with diabetes	11.000 to 12,000 children are diagnosed each year with diabetes	1994	U.S. Dept. of Health & Human Services
	Definition	"Quote" p. 3	1994	U.S. Dept. of Health & Human Services
	Insulin	Prior to insulin children died prematurely or had growth retardation	1993	Clarke, Vance, & Rogol
		Over 95% of children with IDDM survive into adulthood	1996	Orr, Fineberg & Gray
Medical Advances	Insulin	1923-most Western countries have insulin to treat diabetes	1993	Bliss
	Glucose monitors	HBGMs shown to be as accurate as laboratory testing	1992	Tate, Clements, & Walters
Diabetes-diagnosis and adjustment	Conse-quences	Chronic lower levels of hyperglycemia can result in kidney failure, eye damage, & premature death	1994	U.S. Dept. of Health & Human Services
Confounding Variables	Model	Organization of research	1977	Bronfenbrenner
	Individual-Psycho. Factors	Depression due to external locus of control Depression in newly diagnosed adolescents was a mourning reaction in their grief process	1987 1979	Grossman Kovacs
		Good coping skills for minor daily stress equals better diabetes control in adolescents	1986	Hanson & Pichert
		Good communication & ability to resolve conflicts positively impacted ability for good control	1993	Wysocki
		High social competence under stress was not linked with poor metabolic control, but poor social competence combined with stress was correlated with poor control	1987	Hanson, Henggeler & Burghen

Research Topic	Subtopic	Result	Date	Researchers
Confounding variables cont'd..	Weight issues & eating disorders	25% of 10,000 students in grades 9-12 felt they were too fat	1996	Felts
	.	1970 study found that 34.6% of the females & 14.4% of males felt they were too fat	1979	Stuart & Jacobson
		Male & Female young adults with IDDM weighed significantly more than their nondiabetic peers	1992 1992 &1989	Peveler, Fairburn, Boller, & Dunger Steel, Young, Lloyd & MacIntyre
		Weight gain of IDDM adolescents may cause the undesirable side effect of excessive weight loss	1995	Butler & Wing
		From 1960-1980 there were several reports of adolescents with IDDM who developed eating disorders	1990	Marcus & Wing
		However, there were reports of no differences in eating disorders between adolescents with IDDM and control groups without IDDM	1989 1985 1986 1987 1989 1990 1991 1992 1992	Birk & Spencer Hudson, Wentworth, & Pope Rodin, Johnson, Garfinkel, & Kenshole La Greca, Schwarz & Satin Stacin, Link & Reuter Powers, Malone, Coovert & Schulman Fairburn, Peveler, Davies, Mann & Mayou Peveler, Fairburn, Boller, & Dunger Striegel-Moore, Nicholson & Tamborlane

Research Topic	Subtopic	Result	Date	Researchers
Confounding variables cont'd.	Weight issues & eating disorders	However, there were reports of no differences in eating disorders between adolescents with IDDM and control groups without IDDM	1991 1986	Rodin, Cravel, Littlefield, Murray & Daneman Rodin, Johnson. Barfinkel, & Kenshole
		IDDM may accelerate the onset of eating disorder in adolescent females	1986 1986	Rosmark, Berne, Holmgren, Lago, Rengolm & Sohlberg Rodin, Johnson, Garfinkel, Daneman & Kenshole
		Eating disorders in adolescents with IDDM may result from a combination of restricted diets, feelings of deprivation, weight gains from excessive insulin	1984 1985 1989 1989 1990 1990 1992	Polivy, Herman, Olmsted & Jazwinski Polivy & Herman Stacin, Linke & Reuter Steel, Young, Lloyd & MacIntyre Marcus & Wing Steel, Lloyd, Young & MacIntyre Peveler, Fairburn, Boller & Dunger
		Individuals with IDDM may manipulate by misuse of insulin	1995	Butler & Wing
		Women with IDDM often use insulin restrictions for weight control	1989	Stancin
		In a study of 93 women with IDDM 40% reported reducing insulin as a method of weight control	1987	La Greca, Schwartz & Satin
Family		Family especially parents are very important in the care of diabetes for the adolescent	1985	Bowman

Research Topic	Subtopic	Result	Date	Researchers
Family cont'd.	Stress	Increased parental stress resulted in poorer diabetic control	1992	Mengel, Lawler, Volk, Viviani, Dees & Davis
		Families from lower socioeconomic levels with marital difficulties had a higher prevalence of psychiatric difficulties following the diagnosis of diabetes	1985	Kovacs, Feinberg, Paulauskas, Findelstein, Pollock & Crouse-Novak
		After initial adjustment, adolescents & families are generally able to cope adequately with diabetes care	1996 1985 1986 1987	Jacobson Kovacs, Finkelstein, Feinberg, Krous-Novak, Paulauskas, & Pollock, Kovacs, Brents, Steinberg, Paulauskas & Reid Jacobson, Hauser, Wolfsdorf, Houlihan, Milley, Herskowitz, Wertlieb & Watt
	Parental support & involvement	Children with IDDM who perceived their families as being highly organized demonstrated fewer behavioral problems	1986	Wertlieb, Hauser & Jacobson
		Parental support was directly related with adherence especially with younger children with IDDM	1987	Hanson, Henggeler & Burghen
	Parenting style & conflict resolution	Adolescents with IDDM who perceived their parents as dominating & controlling had poorer metabolic control while those who perceived that they had a positive relationship with both of their parents and that both of their parents supported their autonomy demonstrated good control	1982	Marrero, Lau, Golden, Kershnar & Myers

Research Topic	**Subtopic**	**Result**	**Date**	**Researchers**
Family cont'd.	Parenting style & conflict resolution	Family cohesion & ability to resolve conflict were correlated with good control for adolescents with IDDM	1990	Hauser, Jacobson, Lavori, Wolsdorf, Herskowitz, Milley, Bliss, Wertlieb & Stein
	Mother & daughter relationships	There is a great deal of conflict between mothers & daughter with diabetes	1985	Bobrow & AvRuskin
		Compliance was better in younger girls if mothers had taken an active role in the management & treatment of the disease	1985	Bobrow, AvRuskin, & Siller
		Mothers of children with IDDM felt that they were less attached to their child, perceived themselves as less healthy, and felt that they received less support from their husbands than did a control without children that had a chronic illness	1989	Hauenstein, Marvin, Snyder & Clarke
		Adolescents who have difficulties with coping with IDDM respond well when taught in a group setting how to respond to problems resulting from IDDM	1989 1988 1982	Bernbaum, Albert, & Brusca Padgett, Mumford, Hynes & Carter Marrero, Myers, Golden, West, Kershnar & Lau
	Responsibility	There is an assumption that adults are responsible for minor children Parents & adolescents felt they were less able to care for IDDM than did health professionals	1989 1992	McCormick & Brooks-Gunn Wysocki, Meingold, Abrams, Barnard, Clarke, Bellando, &Bourgeois
		Age alone is not the best indicator of when to give the adolescent the responsibility of self-care	1989	Follansbee

Research Topic	Subtopic	Result	Date	Researchers
Family cont'd.	Responsibility	54% of adolescents with IDDM made errors in their judgment about urine testing	1980	Epstein, Coburn, Becker Drash & Siminero
		Transferring older adolescents to an adult focused diabetes program does not appear to negatively impact their diabetes control	1996	Orr, Fineberg & Grey
		Of 59 young adults who responded to a questionnaire, only 68% tested their blood at least once a day and 12% never tested their blood	1995	Dunning
		Frequent daily testing & injections contributed to better diabetes management	1988	Diabetes Control & Complications Trial
		Parents should remain involved with their teen's diabetes care	1995	Daneman
Health Care	Access to medical care	Access to health care is one of the most important aspects of care	1985	Bowman
	Compliance	Insulin resistance occurs during puberty in normal children & children with IDDM	1986	Amiel, Sherwin, Simonson, Lauritano & Tamborlane
		People with chronic illnesses often don't follow doctor's orders	1982	Stewart & Sullivan
			1992	Peveler, Fairburn, Boller, & Dunger
			1992	Steel, Lloyd, Young, & MacIntyre
			1990	Steel, Young, Lloyd, & MacIntyre
			1995	Butler
		In a study with 44 pediatric patients with IDDM, 70% who were in recurrent diabetic ketoacidosis were not taking their insulin & two thirds of this admitted to not taking their insulin	1985	Golden, Herrold & Orr
Diabetes	Complications	Poor control can lead to kidney disease, kidney failure, eye disease & blindness	1994	Anderson, Anderson, & Glanze
			1995	The DCCT Research Group

Research Topic	**Subtopic**	**Result**	**Date**	**Researchers**
Diabetes cont'd.	Standard for good management of diabetes (glycos below 10%)	Increased risk with higher glyco ranges	1996 & 1995	The DCCT Research Group
			1994	Anderson, Anderson, & Glanze
			1992	Tate, Clements, & Walters
		People with diabetes ideally should have 3 to 4 glycos a year	1996 & 1995	The DCCT Research Group
			1994	Anderson, Anderson, & Glanze
			1992	Tate, Clements, & Walters
Family implications	If long term neglect leads to severe diabetic complications such as kidney problems, blindness, etc.	Someone must care for the person with diabetes often giving up employment or family must decide to put the person in a home	1991	Rosenberg
Technology	Quality of life	It is believed that advancements of technology (at reasonable cost) can provide the adolescent with diabetes a more normal life style	1991	Muller

APPENDIX B

APPENDIX B
FLYER FOR MAILINGS

MICHIGAN STATE UNIVERSITY
CHILD HEALTH CARE

A110 Clinical Center
E. Lansing, MI 48824-1313
517-353-3241

DIABETES INTERVIEW

The Michigan State University Pediatric Diabetes Clinic is conducting a research project of teenagers (13 to 18 years of age) who have Type I diabetes. It is hoped that the information gathered with this research will be significant to assist professionals to improve the care of adolescents with diabetes. We value your teenager's input into this project.

The research will involve speaking with your child in private for one interview that lasts 30 to 60 minutes. This will be conducted at a time and place of your convenience (usually either in your home or at the clinic). **Your teenager will earn $10 for their time in this interview.** Interviews will be conducted in the next two to three weeks. Funding is limited and interviews will be scheduled on a first-come-first serve basis. Please telephone immediately for an appointment.

Interviews are confidential and voluntary and whether or not your teenager participates in this interview, the extent of his/her participation, or the results of the answers will not in any way affect medical care, nor be shared individually with the staff at the Diabetes Clinic, and not involve any cost to you or your health care insurer.

Please telephone **517-353-7931** to set you an interview appointment. If no one is available, please be sure to leave a name and phone number on the answering machine and the researcher will call you back.

Sincerely,	Sincerely,
Bruce E. Wilson, M.D. Associate Professor Director, Pediatric Endocrinology	Ann Harlan, Researcher

APPENDIX C

Appendix C

FLYER FOR CLINIC

MICHIGAN STATE UNIVERSITY
CHILD HEALTH CARE

A110 Clinical Center
E. Lansing, MI 48824-1313
517-353-3241

DIABETES INTERVIEW

The Michigan State University Pediatric Diabetes Clinic is conducting a research project of teenagers (13 to 18 years of age) who have Type I diabetes. It is hoped that the information gathered with this research will be significant to assist professionals to improve the care of adolescents with diabetes. We value your teenager's input into this project.

The research will involve speaking with your child in private for one interview that lasts 30 to 60 minutes. This will be conducted at a time and place of your convenience (usually either in your home or at the clinic). **Your teenager will earn $10 for their time in this interview.**

Interviews are confidential and voluntary and whether or not your teenager participates in this interview, the extent of his/her participation, or the results of the answers will not in any way affect medical care, nor be shared individually with the staff at the Diabetes Clinic, and not involve any cost to you or your health care insurer.

Please telephone **517-353-7931** to set up an interview appointment. If no one is available, please be sure to leave a name and phone number on the answering machine and the researchers will call you back.

Sincerely,

Bruce E. Wilson, M.D.
Associate Professor
Director

Sincerely,

Ann Harlan, Researcher

APPENDIX D

APPENDIX D

PERMISSION AGREEMENT

MICHIGAN STATE UNIVERSITY - CHILD HEALTH CARE

A110 Clinical Center
E. Lansing, MI 48824-1313
517-353-3241

PERMISSION FOR DIABETES INTERVIEW

I ____ give permission
(print parent's name)

for my child ___________________________________ to be interviewed
(print child's name)
by a researcher who is a Ph.D. candidate at Michigan State University to assist them in understanding what is taking place in the lives of adolescents with diabetes.

I understand that these interviews will be conducted with the adolescent in private, either at the clinic or in my home, and that the results will be combined with other teenagers' results so that both of our names will be kept anonymous. At my request, the combined results will be made available to me after the data is analyzed.

The interview will take from 30 to 60 minutes, depending on the extent of my child's answers.

The interviews will be taped to guarantee that the correct information is analyzed. However, if either of us does not want the interviews to be taped, we can check the line below and a recorder will not be used. Results will them be handwritten.

I understand that I may stop the interview at any time or refuse to answer any questions.

I understand that these interviews are voluntary and whether or not we participate in this interview, the extent of our participation, or the results of the answers will not in any way affect medical care nor be shared individually with the staff at the Diabetes Clinic.

____
Parent or Guardian's Signature

____
Teenager's Signature

____
Witness's Signature

____
Date

_ Please do not record the interview

APPENDIX E

APPENDIX E
INTERVIEW QUESTIONS

MICHIGAN STATE UNIVERSITY
CHILD HEALTH CARE

A110 Clinical Center
E. Lansing, MI 48824-1313
517-353-3241

INTERVIEW QUESTIONS - PAGE 1

INTRODUCTION:

You know more about diabetes than anyone. As the expert, I really want to know what it is like to have diabetes. I will be asking you questions about the different aspects of diabetes.

DIAGNOSIS:

The first section is about being diagnosed with diabetes.

1. How old were you when you were diagnosed with diabetes?

2. Do you remember when you were diagnosed? Tell me about it.

DIABETES CARE:

The second section asks about caring for your diabetes.

3. Who does your blood sugar tests? How often?

4. Who draws up your insulin? How often?

5. Who gives your shots? How often?

6. How often is your insulin adjusted? How does this get adjusted?

7. Do you know the results of your last glycohemoglobin? What does that number mean?

APPENDIX E
INTERVIEW QUESTIONS
PAGE 2

IMPACT OF DIABETES:

The third section asks questions about how diabetes affects your life.

8. In your experience, what is the most difficult part of having diabetes?

9. Some teenagers your age have difficulty controlling their diabetes. Why do you believe that this happens?

10. Some teenagers have trouble keeping up with their diabetes care and may skip shots or reduce insulin. How about you? How often have you ever skipped a shot or reduced your insulin?

11. Is there a time when a teenager might not tell the truth about their blood sugar numbers or insulin shots? Have you ever been in this position? What was it like?

12. How many times have you been hospitalized for diabetes? When did this happen?

13. Do you worry about having diabetes? What do you worry about?

OTHER FACTORS THAT MAY INFLUENCE DIABETES:

The fourth section asks about other things that may indirectly impact (or affect) your diabetes.

14. Some teenagers are more satisfied with the way that they look than others. How satisfied are you with how you look?

15. Some teenagers are satisfied with their weight and some are not. What about you? (If not answered in #9)

16. Some teenagers don't eat so that they can be thin or eat food and then wish that they had not, so they make themselves throw up or take something like a laxative to make themselves go the bathroom. Do you know any teens who do this? What about you?

APPENDIX E
INTERVIEW QUESTIONS
PAGE 3

17. What types of things can't you do because of the diabetes?

18. What types of sports or activities are you involved in at school, in the community, or at church? How often do you do these things?

SUPPORT SYSTEMS:

The fifth section asks questions about people who might be helpful for you in coping with diabetes and problems in life.

19. Who is the most helpful person in your family for you? What do they do that is helpful?

20. Who is the person in your family with whom you have the most conflict or arguments? What happens when you have problems with them?

21. Is there another adult, that does not live in your home, that you can talk to about your diabetes? How are they helpful?

22. Do you have a friend/family member who you can talk to about almost anything, including your diabetes? Tell me about them.

23. When you have a problem with your diabetes, who do you turn to and how do they help?

MEDICAL CARE:

The sixth section asks about the medical care that you get for your diabetes.

24. Do you go anywhere else for diabetes care besides the MSU Clinical Center? What makes you go there instead of MSU?

25. What is the best part (s) of coming to the MSU Clinical Center, if there is one?

APPENDIX E
INTERVIEW QUESTIONS
PAGE 4

26. What is the worst part (s) of coming to the MSU Clinical Center, if there is one?

HELPING OTHERS:

The last section asks questions that are designed to help other kids with

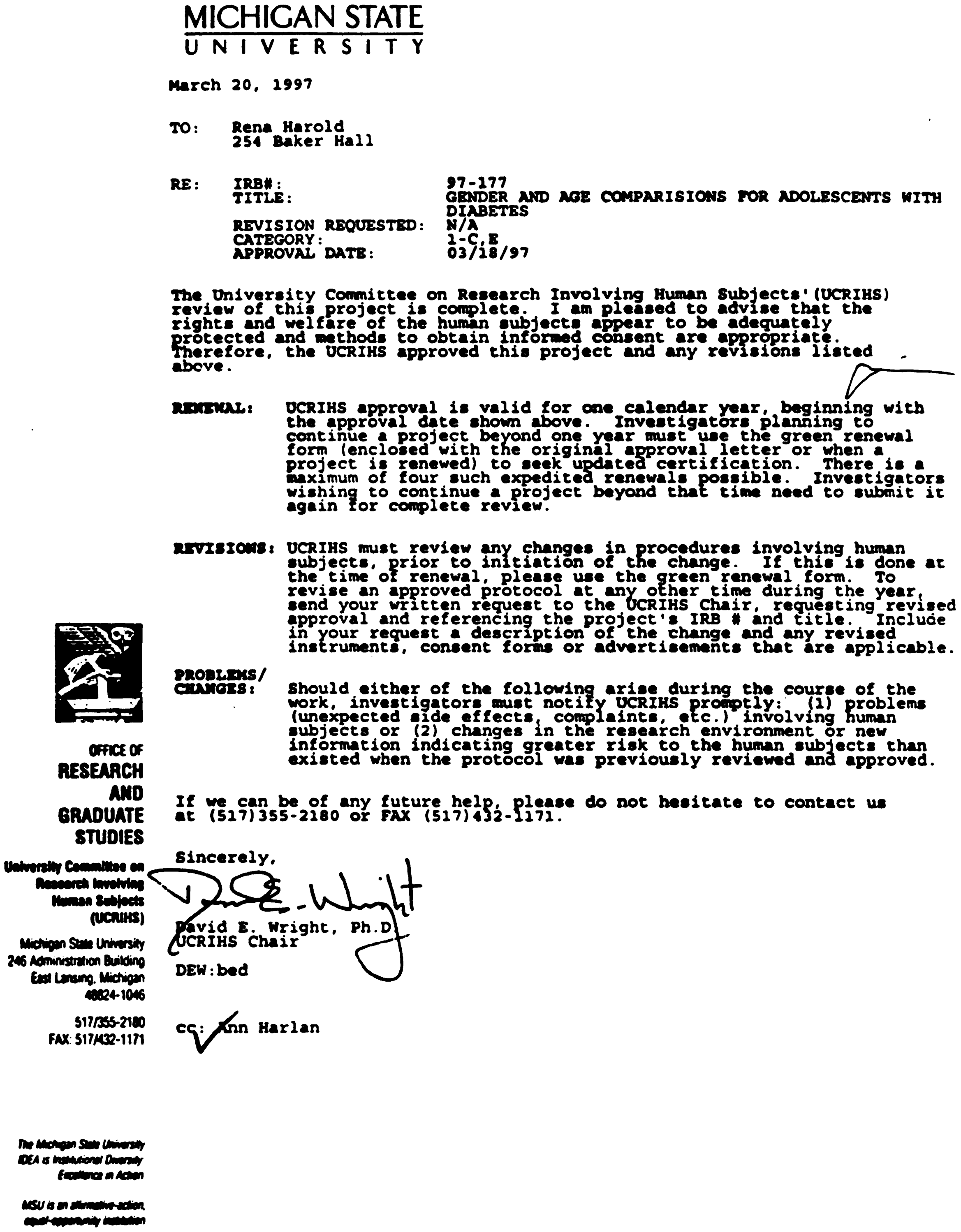
27. Some people have strong stereotypes (or beliefs) about what age or gender of teenagers has more trouble controlling their diabetes. Who do you think has more trouble controlling their diabetes and why?

28. What do you think would be helpful for other kids your age to know about diabetes?

29. What would you tell parents or doctors about living with diabetes?

Thank you for your time in this interview. Your answers will be very helpful to other teenagers. I'll combine your answer with those of other teens and present them in my research.

APPENDIX F



MICHIGAN STATE
UNIVERSITY

March 20, 1997

TO: Rena Harold
254 Baker Hall

RE: IRB#: 97-177
TITLE: GENDER AND AGE COMPARISIONS FOR ADOLESCENTS WITH DIABETES
REVISION REQUESTED: N/A
CATEGORY: 1-C,E
APPROVAL DATE: 03/18/97

The University Committee on Research Involving Human Subjects'(UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Ann Harlan

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

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