This is to certify that the
dissertation entitled

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

presented by

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has been accepted towards fulfillment
of the requirements for the

Doctoral degree in Family and Child Ecology

Major Professor's Signature

May 10, 2006

Date

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

By

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Department of Family and Child Ecology

2006

ABSTRACT

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

By

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The overall purpose of this research study was to investigate the impact of perceived parental support and different parenting styles upon adherence to diabetic health management, metabolic control and perceived quality of life for adolescents diagnosed with Type 1 insulin dependent diabetes. This cross-sectional quantitative causal comparative study was carried out in a natural setting. One hundred and two adolescents, between 12 and 18 years of age, diagnosed with insulin dependent diabetes for at least one year, and attending a large pediatric endocrinology clinic in West Michigan participated.

The study investigated the relationships between the adolescent's perceived level of parental support and the adolescents' adherence, metabolic control and quality of life. Additionally, differences in the adolescent's adherence, metabolic control and quality of life were examined in terms of the type of parenting style used. Parenting style was determined by the adolescent's perception of his/her parents in terms of demandingness and responsiveness. Based on these two dimensions, parents were then classified into one of four parenting style groups: authoritative, authoritarian, permissive, or neglectful.

Results indicated that perceived parental support was significantly correlated with adherence and that approximately 17% of the variation in adherence was explained by perceived parental support. No significant relationship was found between perceived parental support and metabolic control. Quality of life, as

assessed through the satisfaction with diabetes subscale, showed a significant relationship with parental support especially after two erroneous outliers were removed.

Adolescents who perceived their parents to have authoritative parenting styles had better adherence to their prescribed treatment plan compared to those who perceived their parents to have authoritarian, permissive or neglectful parenting styles. Parenting style was able to explain approximately 12% of the variability in adherence. Additionally, adolescents who perceived their parents to have authoritative parenting styles had better perceived quality of life than did adolescents who perceived their parents to have authoritarian or permissive parenting styles. These findings have implications for health care workers trying to assist adolescents and their families in the management of their diabetic health care.

DEDICATION

This study is dedicated to my husband, Jeff Gartner, for his love and many hours of editorial support. It is also dedicated to my daughters Lindsay, Aubrey and Chelsea, my mother Sylvia T. Mlynarczyk, and my deceased father Joseph E. Mlynarczyk. Their love and support have been a constant source of inspiration and encouragement.

ACKNOWLEDGMENTS

I sincerely extend my appreciation to all those who facilitated my progress toward completion of this dissertation. I wish to thank Dr. Robert Boger, chairperson of my dissertation committee, for his dedicated mentorship, scholarly guidance, encouragement and support. I also wish to thank Dr. Robert Griffore, Dr. Holly Brophy-Herb, and Dr. Linda Spence, members of my dissertation committee, for their expertise, constructive contributions, guidance and support.

My appreciation is also extended to faculty colleges and friends for their much needed encouragement and support, especially to Tam George for her emotional support and encouragement, to Nicki Grinstead for her detailed editing and encouragement, and to Sherry Knoppers for her support and friendship as we shared many aspects of this journey together. I also wish to thank Sister JoAn for her incessant prayers and emotional support, my neighbors Don and Marianne Strazisars for their humor and encouragement, the Kirkhof College of Nursing for their support, and several dear friends for their understanding, support, and encouragement.

I would also like to thank Dr. Wood, the staff, and research nurses affiliated with the Pediatric Endocrinology and Diabetes Clinic for their assistance with this research project. Grateful acknowledgment is also made for the financial assistance gained through the Paolucci Scholarship, Marie Dye Dissertation Completion Fellowship, and the Jean Davis Schlater Dissertation Fellowship. Lastly, I would like to thank my husband, daughters, mother, brother, and sister-in-law for their love, understanding and sustaining support.

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CHAPTER 1

INTRODUCTION

Insulin dependent diabetes mellitus (IDDM) or Type 1 diabetes is a potentially life threatening illness. It is characterized by high blood glucose levels resulting from a defect in insulin production that can lead to serious complications such as retinopathy, nephropathy and neuropathy, or even an early death. It is considered the diabetes of childhood, with approximately 75% of diagnosed cases under the age of 18 (Hockenberry, Wilson, Winkelstein, & Kline, 2003). According to the most recent statistics from the National Diabetes Information Clearinghouse (2005), there are approximately 177,000 children and adolescents with IDDM in America today. Adolescents, especially those in their mid and late teens, are particularly at risk for health complications related to poor diabetic management.

The results from the Diabetes Control and Complications Trial (1993) found one can significantly delay the onset of complications by consistently lowering blood glucose levels to near normal. Successful medical treatment of IDDM depends not only on appropriate prescribed treatment, but also on compliance with treatment. Effective management is measured by good glycemic control (near normal blood glucose levels). Self-care management includes multiple daily blood glucose monitoring tests, insulin injections or use of an insulin pump, dietary adherence and exercise. It is during the adolescent period that proper health care management of diabetes falters.

To delay or prevent serious health problems or even death researchers and health care providers need to discover ways of helping adolescents to better

manage their diabetes. Previous research studies have shown compelling relationships between parental support and a decrease in adolescent health risk behaviors. Further research can enhance our understanding of the relationship between family or parental support and adolescent health and how this might aid the adolescent in better management of his or her diabetes.

This research investigated the effect of parental support on the adolescents' management of their diabetes. This first chapter introduces the domain of inquiry, specifies the problem of the study, describes its significance and presents an overview of the methodology used including research objectives, research questions, hypotheses and definitions. The chapter concludes with delineating the conceptual framework and conceptual map.

Statement of the Problem

This study explored specific dimensions of parental support (perceived support and parenting styles) that enable the adolescent, 12 to 18 years of age, to most effectively manage his or her insulin dependent diabetic health care and promote a sense of quality of life. More specifically, this study explored parental support as perceived by the adolescent and measured by the Diabetes-specific Parental Support for Adolescent's Autonomy Scale (Hanna, DiMeglio, & Fortenberry, 2004), and differences in four parenting styles (authoritative, authoritarian, permissive, and neglectful) as measured by the Parenting Style Index–II [PSI-II] (Darling & Toyokawa, 1997) as they related to the adolescent's management of diabetic health care measured through adherence using the Diabetic Behavior Rating Scale [DBRS] (McNabb, Quinn, Murphy, Thorp, & Cook, 1994), metabolic control (HgbA1c) and the adolescent's perceived quality

of life as measured by the Diabetes Quality of Life – Youth scale [DQOLY] (Ingersoll & Marrero, 1991).

Significance of the Problem

Over the last two decades, researchers have looked increasingly at social support issues and their impact on adolescent health in terms of diabetic care management. The adolescent period is a time when good diabetic health management and the resultant metabolic control falter (Anderson, Auslander, Jung, Miller, & Santiango, 1990; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Jacobson et al. 1990; Schafer, McCaul, & Glasgow, 1986). Researchers of children and adolescents with diabetes have determined that children and adolescents with poorly managed diabetes care had more dependency conflicts, anxiety, depression, low self-esteem, social dependency and poor ego development (Hauser & Pollets, 1979). The majority of studies seem to reflect a strong relationship between social support, more specifically parental support, and adolescent health. In a classic study, family support was identified as highly valuable to adolescents in terms of diabetic health management (La Greca et al. 1995). Weinger, O'Donnell, & Ritholz (2001) found further evidence to support this as they explored adolescent views of what types of parental support were helpful (understanding and reassurance). Tangible forms of support were also found to be very valuable (Hanna & Guthrie, 2001).

Diabetic health management appears to be positively influenced by positive parent support. However, the conceptualization of parental support has not been clearly defined in many cases nor has it been used consistently. Social support is multidimensional. It can focus on tangible, informational, and emotional types of support, or it can focus on parental warmth or family cohesion and adaptability.

Some studies have reported variant findings related to the benefits of parental support. While several researchers have found that having a supportive family contributes to better adherence and metabolic control (Anderson, Miller, Auslander, & Santiago, 1981; Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992; Jacobson, et al. 1994; Wysocki, 1993) other researchers have found that adolescents with very supportive families have had unremarkable/poor adherence or metabolic control outcomes (Burroughs, Pontious, & Santiago, 1993; Delahanty & Halford, 1993; Kovacs, Goldston, Obrosky, & Iyengar, 1992; Miller-Johnson et al. 1994; White, 1990). In some cases it has not always been clear which aspects of support were studied, how support was defined or whether positive and/or negative aspects of parental support were considered.

It is possible that the conflicting findings may be due to unclear conceptualizations, failure to look at various dimensions of support, inadequate measurement tools or due to examining parent support behaviors in isolation and failing to examine the parent-child relationship in terms of parenting style. In a recent review of current literature, Anderson (2004) identified a link between parenting styles and glycemic control and adherence, noting that families with more cohesion, support and affection, reflecting an "authoritative" style of parenting were related to greater adherence levels and better glycemic control. Families that were characterized by more conflict, criticism and parental restrictiveness, an "authoritarian style," were associated with lower levels of adherence and poorer glycemic control. A study by Davis, et al. (2001) confirmed these finding with a population of preschool and elementary school children 4-10 years of age. This study warrants a closer look to see how parenting styles and its relationship to health might be applied to adolescents as well.

The construct of parenting style is used to capture normal variations in the parents' attempt to control and socialize their children. It reflects a broad pattern of parenting (Baumrind, 1991). To look only at specific parenting characteristics or behaviors in isolation may be misleading. As numerous studies have suggested, positive parent–child relationships are critical to adolescent development (Bennet & Westera, 1994; La Greca et al.1995). Parenting style has been shown to impact the parent-child relationship (Baumrind, 1971, 1991; Glasgow, Dornbusch, Troyer, Steinberg, & Ritter, 1997) and may further the understanding of the family milieu and its relationship to the care of a child/adolescent with diabetes. Although, some characteristics attributed to various parenting styles have been studied (warmth, control), to date, no one has studied the relationship between "parenting-style" (exclusively) and adolescent's diabetic health care management.

In a recent "Report on the Task Force on the Family" appointed by the American Academy of Pediatrics (Anonymous, 2003), it was noted that the health and well-being of children are "inextricably linked" to the health, social circumstances and "child-rearing practices" of the parents. Children need high quality parenting with unconditional love, warmth and affection, thoughtful and firm limit setting, and responsive, flexible, respectful, and consistent behavior patterns. Generally, the task force suggested that the "authoritative parenting style" leads to having children who are more likely to be happy, creative, and cooperative. These children also seem to exhibit higher self-esteem and perform better academically and socially. It was further recommended that pediatricians become more proactive in discussing effective parenting practices with their respective families. Studying the effects of parenting styles on children's health

and more specifically adolescents with diabetes can only contribute to our understanding of effective parenting practices that lead to better health for these populations.

Research Objectives

The overall purpose of this research study was to investigate if perceived parental support and different parenting styles affect adherence to diabetic health management, metabolic control and perceived quality of life for adolescents aged 12 to 18, diagnosed with insulin dependent diabetes. In order to reach this goal, two specific objectives were developed to guide the research as follows:

- To investigate the relationship between levels of perceived parental support and adolescents' adherence, metabolic control and perceived quality of life.
- To investigate differences in adherence, metabolic control and perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive, or neglectful parenting styles.

Research Questions

In order to accomplish these objectives, the following research questions will be addressed.

1. Is there a relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan?
2. Is there a relationship between adolescents' perceived level of parental support and their metabolic control?
3. Is there a relationship between adolescents' perceived level of parental support and their perceived quality of life?
4. Is there a difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles?
5. Is there a difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles?
6. Is there a difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles?
7. Is there a difference in metabolic control between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles?
8. Is there a difference in metabolic control between adolescents who perceive their parents to have authoritative parenting styles and

adolescents who perceive their parents to have permissive parenting styles?

9. Is there a difference in metabolic control between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles?
10. Is there a difference in perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles?
11. Is there a difference in perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles?
12. Is there a difference in perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles?

Research Hypotheses

(Please note: IV stands for independent variable and DV stands for dependant variable).

Research Question 1 -- IV –Perceived Parental support DV – Adherence

HO 1 There is no relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan.

HA 1 There is a relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan.

Research Question 2 -- IV –Perceived Parental support DV – Metabolic Control

HO 2 There is no relationship between adolescents' perceived level of parental support and their metabolic control values (HgbA1c).

HA 2 There is a relationship between adolescents' perceived level of parental support and their metabolic control values (HgbA1c).

Research Question 3 – IV –Perceived Parental support DV – Quality of Life

HO 3 There is no relationship between adolescents' perceived level of parental support and their perceived quality of life.

HA 3 There is a relationship between adolescents' perceived level of parental support and their perceived quality of life.

Research Questions 4-6 - IV – Parenting Style DV – Adherence

HO 4 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HA 4 Adolescents who perceive their parents to have authoritative parenting styles will have better adherence to their prescribed treatment plan than will adolescents who perceive their parents to have authoritarian parenting styles.

HO 5 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HA 5 Adolescents who perceive their parents to have authoritative parenting styles will have better adherence to their prescribed treatment plan than will adolescents who perceive their parents to have permissive parenting styles.

HO 6 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

HA 6 Adolescents who perceive their parents to have authoritative parenting styles will have better adherence to their prescribed treatment plan than will adolescents who perceive their parents to have neglectful parenting styles.

Research Questions 7-9 - IV – Parenting Style DV – Metabolic Control

HO 7 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HA 7 Adolescents who perceive their parents to have authoritative parenting styles will have better metabolic control values (HgbA1c) than will adolescents who perceive their parents to have authoritarian parenting styles.

HO 8 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HA 8 Adolescents who perceive their parents to have authoritative parenting styles will have better metabolic control (HgbA1c) than will adolescents who perceive their parents to have permissive parenting styles.

HO 9 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

HA 9 Adolescents who perceive their parents to have authoritative parenting styles will have better metabolic control (HgbA1c) than will adolescents who perceive their parents to have neglectful parenting styles.

Research Questions 10-12 - IV - Parenting Style DV – Quality of Life

HO 10 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HA 10 Adolescents who perceive their parents to have authoritative parenting styles will have better perceived quality of life than will adolescents who perceive their parents to have authoritarian parenting styles.

HO 11 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HA 11 Adolescents who perceive their parents to have authoritative parenting styles will have better perceived quality of life than will adolescents who perceive their parents to have permissive parenting styles.

HO 12 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

HA 12 Adolescents who perceive their parents to have authoritative parenting styles will have better perceived quality of life than will adolescents who perceive their parents to have neglectful parenting styles.

Decision Rule: An alpha of .05 or less ($p < .05$) will be required to reject the null hypotheses

Conceptual and Operational Definitions

Perceived Parental Support.

Conceptual	Perceived parental support refers to the adolescent's perception of his/her parent's support in terms of guidance and non-directive support of various aspects of the diabetic regimen.
Operational	Perceived parental support refers to the adolescent's perception of his/her parent's support in terms of guidance and non-directive support of various aspects of the diabetic regimen as measured by the Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (Hanna et al. 2004).

Parenting Style.

Conceptual	Parenting style refers to the predominant style of parenting used by parents to parent their adolescents. This includes the authoritative, authoritarian, permissive, and the neglectful parenting styles.
Operational	Parenting style refers to the adolescent's perception of parenting style as measured by the Parenting Style Index –II [PSI-II] (Darling & Toyokawa, 1997)), which differentiates between the authoritative, authoritarian, permissive and neglectful style of parenting.

Adherence

Conceptual	Adherence refers to all of the daily self care activities that the adolescents (and family) perform to manage their diabetes.
Operational	Adherence refers to all the daily self-care activities that the adolescents (and family) perform to manage their diabetes as measured by the Diabetic Behavior Rating Scale (DBRS), (Cook, Aikens, Berry, & McNabb, 2001; McNabb, Quinn, Murphy, Thorp, & Cook, 1994).

Metabolic Control

Conceptual	Metabolic control refers to the blood test that allows physicians to obtain an individual's average blood glucose level for the previous three months as a way to assess glucose control.
Operational	Metabolic control refers to the average of the adolescent's last four glycosylated hemoglobin values (HgbA1c). Lower HgbA1c values reflect better glucose control over the past three months.

Quality of Life

Conceptual	Quality of life refers to the subjective impact of diabetes and its daily management on the adolescent's life.
Operational	Quality of life refers to the adolescent's perceived quality of life as measured by the Diabetes Quality of Life Instrument for Youth [DQOLY] (Ingersoll & Marrero, 1991).

Conceptual Framework

The family ecological model provides the conceptual framework for this study. This ecological approach allows for the examination of the interdependence of the family and its interacting environments. In the family ecosystem, the environed unit is comprised of the family members. The family ecosystem supports the development of the individual family members through its roles, rules and interactions. It is this approach that allows one to view the family system's members personal attributes such as health and skills, and the structural attributes of the family such as the authority patterns or styles of parenting, interpersonal and effectual relationships, and patterns of decision making (Andrews, Bubolz, & Paolucci, 1980).

This model would allow the interaction between the family members to be viewed independently or interdependently, such as how the structural attributes of family members and the personal attributes of family members affect each other. This model also reflects how the family unit may interact with other environments such as the health care system. Figure 1 presents a descriptive model that conceptualizes the family as an ecological unit, comprised of individuals who interact interdependently and/or independently within their own system and also with other environments.

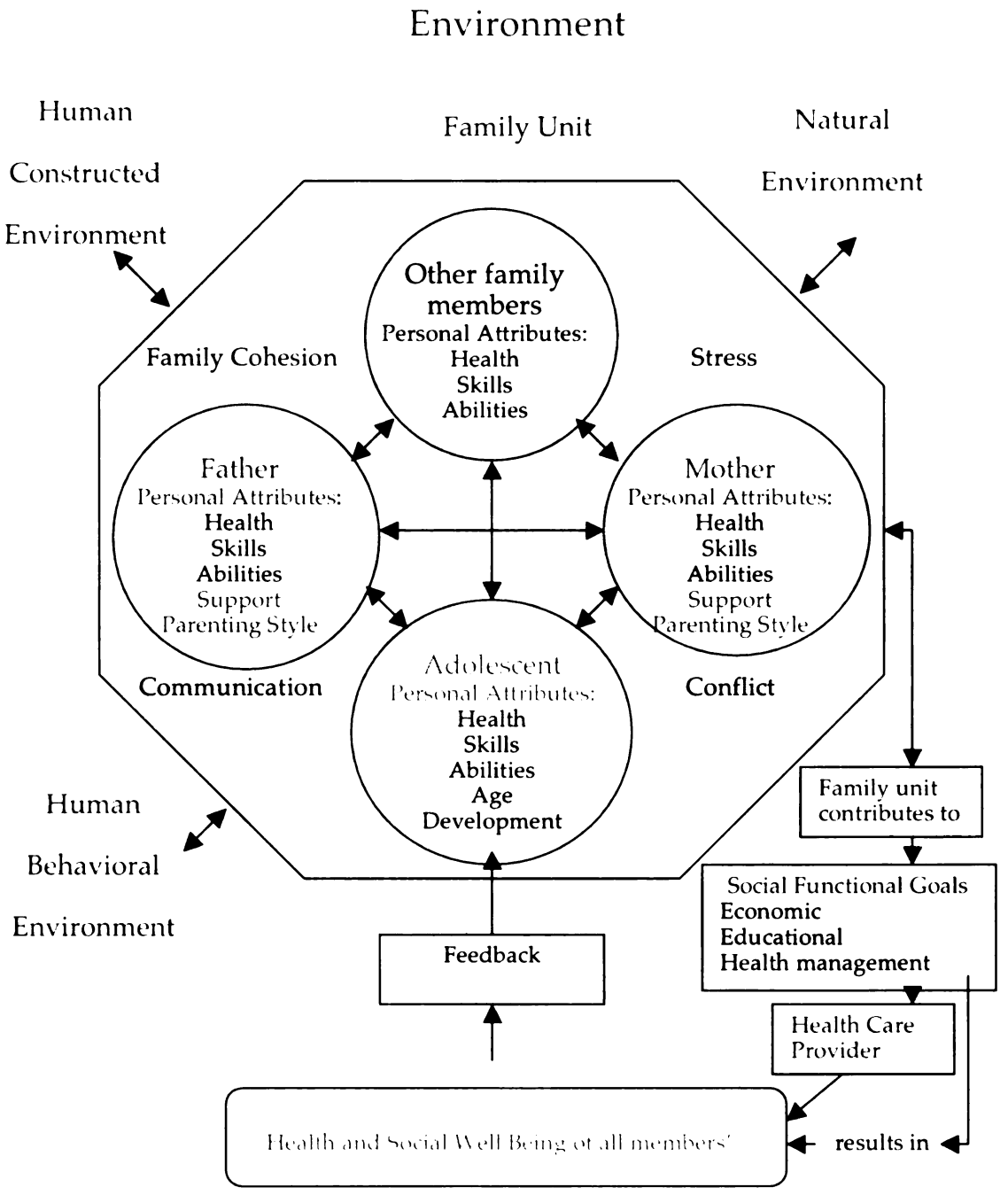

Figure 1. *Conceptual model for family and environment transactions*

(Please note: Images in this dissertation figure are presented in color)

Conceptual Map

For this study it was important to identify the behaviors that demonstrate parental support. To reflect this, a conceptual map was developed to show how the relationship of parental support and use of the authoritative parenting style with responsiveness to adolescents' verbal or non-verbal needs would relate to an adolescent's diabetic health management. This is depicted in Figure 2.

The conceptual map reflects the factors identified by Follansbee (1989) as necessary for an adolescent to assume self-care. When these factors are present and there is adequate parental support, the adolescent would be able to manage the diabetes successfully and achieve better metabolic control. If, on the other hand, the parents were not supportive, lacked the necessary knowledge or skills, had poor communication about responsibilities, and used non-authoritative parenting styles, then the outcome would more than likely be poor diabetes management. Additionally, as the literature supports, the adolescent's perception of parental or family support is also related to good diabetes management (Burroughs, Harris, Pontious, & Santiago 1997).

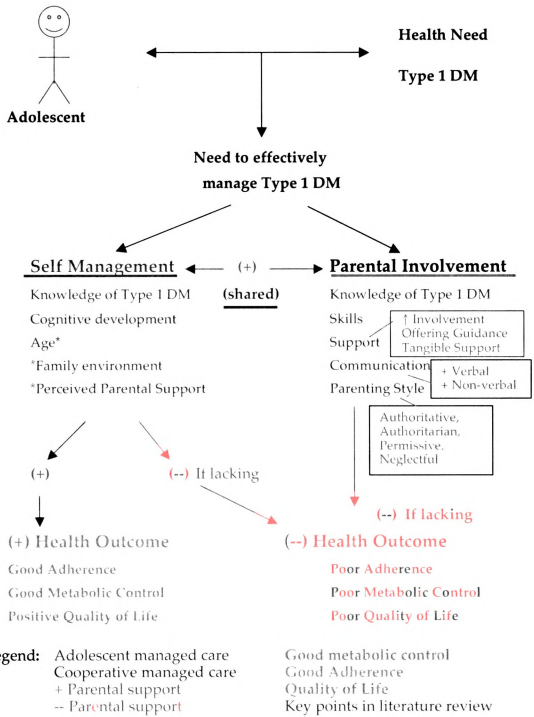

Figure 2. Conceptual Map. Proposed model of the significance of parental support in an adolescent's management of Type 1 Diabetes Mellitus (DM)
(Please note: Images in this dissertation figure are presented in color)

CHAPTER 2

REVIEW OF THE LITERATURE

Issues affecting Adolescent Management of Type 1 Diabetes

The complex and intensive treatment for Type 1 diabetes can be difficult to maintain, especially for adolescents who are experiencing significant social, psychological, emotional, and physiological changes. Successful and cost effective medical treatment of children depends not only on adequate prescribed treatment, but also on adolescents' compliance with treatment. Adolescence has often been a period during which compliance with prescribed diabetic treatment plans falter significantly (Anderson et al. 1990; Anderson et al. 1997; Jacobson et al. 1990; Schafer et al. 1986). Issues affecting diabetic management are multifaceted, but several factors contributing to adolescent non-compliance are highlighted below:

1. The developmental demands of adolescence may often conflict with the diabetic regimen, compelling some adolescents to choose between them. Adolescents often find the required strict self-discipline and responsible behavior for self care very burdensome (Anderson et al. 1990). For the adolescent, it is often more desirable to conform with peer groups and strive for independence from adults, both of which, may contribute to noncompliance with diabetic management (Jacobson et al. 1990; La Greca, Follansbee, & Skyler, 1990)
2. Family relations have also been shown to affect glycemic control. Some studies report a positive relationship between family relations and metabolic control (Anderson et al. 1981; Hanson, DeGuire, et al. 1992;

Jacobson et al. 1994; and Wysocki, 1993), and others report a negative relationship between family relations and metabolic control (Burroughs et al. 1993; Cedarblad, Helgesson, Larsson, & Ludvigsson, 1982; Delahanty & Halford, 1993; Kovacs et al. 1992; Miller-Johnson, et al. 1994; Minuchin et al. 1975; White, 1990;). For many adolescents with chronic illnesses, compliance issues are exacerbated because of conflicts that often arise in the parent-child relationship (Miller-Johnson, et al. 1994).

3. A study by Overstreet et al. (1995) found that the nontraditional family structure as compared to the traditional two-parent nuclear family, was related to significantly poorer metabolic control.
4. Issues regarding the transfer of responsibilities to self-care at a time when adolescents normally are assuming greater autonomy and independence can further compound the problem. Transferring control of diabetes management from parent to a young adolescent prematurely has shown a marked deterioration in the child's metabolic control (La Greca et al. 1990).
5. Some studies have shown that parent-adolescent communication can negatively influence metabolic control (Anderson & Coyne, 1993; Hanna, Juarez, Lenss, & Guthrie, D., 2003). Hanna et al. (2003) found that the more adolescents communicated a need for support from parents, the more they received. However, when there was less discussion and agreement with parents regarding whose responsibility it was for certain diabetes management tasks, the adolescent experienced worse metabolic control.

6. In addition, the shift in family and peer relationships, common during adolescence, can amplify the complexity of the issue. Although the role of the family is still instrumental in the adolescent's life, friends begin to provide much of the adolescent's emotional and social support (Jacobson et al. 1987; La Greca, 1992).
7. A few other researchers found that age seemed to play a role in good metabolic control. It was found that older adolescents with the strongest self-concept, the most social support, and the most knowledge about Type 1 diabetes were more non-compliant than younger adolescents and had poorer metabolic control (Delahanty & Halford, 1993; White, 1990). It was postulated that perhaps these adolescents were engaging in power struggles with their parents and were using compliance as a control issue. These differences can be explained by developmental age differences and the older adolescents' (15-18 years old) struggle for independence. Additionally, the role of hormonal changes and its deteriorating effect on metabolic control my also be a contributing factor (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986).
8. Adolescents with psychiatric disorders (major affective disorders, conduct or substance use disorders or anxiety disorders) were also found to have more significant compliance issues (Kovacs et al. 1992). These finding were consistent with earlier findings that adolescents with poorly controlled diabetes were found to have more dependency conflicts, anxiety and depression, as well as poorer psychosocial

adjustment (Grey, Tamborlane, & Genel, 1980; Karlsson, Holmes, & Lang, 1988).

Several issues affecting the adolescents' management of their diabetes have been identified. A common thread woven through several of these issues had to do with parent-child relationships and the kind of support offered by parents. Previous research studies did not clarify how parental support specifically related to diabetic health management or predicted which individual may be at risk for noncompliance and poor metabolic control. Health care providers need to seek ways to intervene in adolescents' behavior to enhance their diabetic management and improve their health. Understanding the importance of social support and more specifically parental support through the adolescent years, may guide health care providers in assisting adolescents and their families with the management of Type 1 diabetes.

This chapter will review the relevant aspects of social support as it relates to the care and management of Type 1 diabetes for adolescents. Literature from the disciplines of nursing, psychology, and sociology were examined on the relevant topics to this domain of inquiry. The review continues with the following topics: theoretical literature on social support, social support and diabetic management, parenting style and quality of life.

Theoretical Literature on Social Support

Social support, a construct studied by sociologists, psychologists and health scientists, serves to identify and explain the nature, significance and outcomes of social relationships. The study of social support derived from the need to understand the relationship of social interactions with respect to the health and well being of the individual. Cohen, Underwood, & Gotlieb (2000) identified two

processes through which social relationships can influence health. The first type involves the exchange of emotional, informational or instrumental resources when there is a perceived need often associated with a stressful experience. In other words, social support refers to social transactions that are "perceived by the recipient or intended by the provider to facilitate coping in everyday life, and especially in response to stressful situations" (Pierce, Sarason, & Sarason, 1990, p. 173).

The other process refers to the health benefits that accrue from the sense of belonging to one or more social groups. This process relates to the belief that others can influence cognitions, emotions, behaviors and biological responses in ways that benefit one's health and well-being. This would include influences on one's self-concept, feelings of self-worth, sense of control, and conformity to behavioral norms all of which can impact one's health (Cohen et al. 2000).

Several theories provided a precedent for the study of social relationships and its significance on health and well-being. One exchange theorist, R. Weiss, postulated that some requirements for psychological well-being might only be met through social relationships (Vaux, 1988). The foundational relationship between mother and child is said to be the key to the ability to establish all later social relationships (Ainsworth, 1979; Bronfenbrenner, 1979).

Three scholars, John Cassel, Gerald Caplan, and Sidney Cobb, could be declared the "Fathers of Social Support." They laid much of the ground work for the meta construct of social support.

John Cassel (1976) was an epidemiologist and physician. He claimed that psychosocial processes play a role in the etiology of disease and that social support can have a profound impact in stress-related disorders.

> He viewed social support as being provided by primary groups, those most important to an individual, and as serving an important protective function, *buffering* or *cushioning* the individual from the somatic or psychological consequences of stressful experiences. Thus, social support was prominent in the health-protective category or psychosocial processes. He advocated the mobilization of social support as a more feasible direction for intervention than attempting to reduce exposure to environmental stressors (Vaux, 1988, p.6).

This last point continues to be an area of focus in the study of social support today. Gottlieb (1981) summed up Cassel's legacy as resting on "the two lines of ecological inquiry he spurred: a) inquiries devoted to analyzing how people's interactions with the social environment conspire to augment their vulnerability to illness and disease, and b) how social forces can be mobilized in these situations for the sake of health protection (p. 23).

Gerald Caplan (1974) worked in the area of preventive psychiatry and community mental health. He also realized the role that social interactions had on the result of life changes and crises. He adopted several of Cassel's ideas as they complimented his own, especially regarding social feedback. He viewed support systems not only as including family and friends, but also groups and neighborhood settings that provided informal services. "With support strategically placed in each of the settings where an individual spends time, he or she might be protected almost completely from the adverse effects of stress" (Vaux, 1988, p.7). He also saw the role that formal caregivers play in the collaboration with or development of informal support systems.

Sidney Cobb (1976) shared a view similar to Cassel and Caplan regarding the importance of social support and its relationship to stress and well-being. He

more clearly defined social support as "information" that would lead a person to believe that he/she was loved and cared for, valued and belonging to a group with shared communication and obligation. Cobb further explained that this "information" served to fulfill needs and to protect from adverse consequences of crises and stressors (Vaux, 1988). He emphasized that social support was a stress-buffer. Cobb believed that "adequate social support can protect people in crisis from a variety of physical and psychological disorders, presumably through the facilitation of coping and adaptation" (Vaux, 1988, p. 7).

In his study of social support, Vaux (1988) conceptualized social support to include: support network resources, support behaviors, and support appraisals. *Support network resources* refer to the number of persons that a person turns to for assistance (family, friends, peers, co-workers and so forth) or comes in contact with on a daily basis. *Support behaviors* refer to the behaviors that are generally recognized as intentional efforts to help a person. These could be emotional such as listening, offering love, comfort, affection, or advice; or practical, such as financial or material. Supportive behaviors may not always be considered helpful. *Support appraisals* are the subjective evaluative assessment of the supportive network relationships or supportive acts (Vaux, 1988).

The social support network may influence health status directly through information sharing or by motivating healthy behavior. Or, it may affect health indirectly through encouragement to comply with regimes or to maintain health-promoting behavior such as exercise (Stewart, 1994). Network members may provide advice and models of behavior or give support provisions that augment immunity (Bloom, 1990; Cohen & Wills, 1985). Zimmerman and Connor (1989)

found the most helpful supportive behaviors to be supportiveness, encouraging maintenance and modeling health change.

In summary, the study of social support is a study on the characteristics of social relationships that are thought to maintain or promote psychological and physical health. It seems clear that the field of social support grew out of a desire and need to understand how social interactions improve or inhibit health and how to improve health through social interactions.

Social Support and Diabetic Management

In a critical review of the literature on the nature of social support in adolescents with Type 1 diabetes, Burroughs, Harris, Pontious, and Santiago (1997) indicated that the support that the adolescent perceives from his or her family and friends plays a large role in his or her's overall diabetic management. They also indicated that family support played a significant role in helping the adolescent to achieve good metabolic control. The importance of family and parental support as well as other aspects of social support as it relates to the adolescent with Type 1 diabetes will be reviewed.

Family/Parental Support

Several studies in the review by Burroughs et al. (1997) looked at family support characteristics. These included variables such as family cohesiveness, type of support provided, communication effectiveness, and/or perceived helpfulness. A study by Anderson et al. (1981) found that adolescents in good control reported more cohesion and less conflict among family members. These adolescents' parents encouraged them to behave independently, express their feelings directly, and act openly. Adolescents in good control also described family members as more committed, helpful, and supportive of each other

compared to adolescents in fair or poor control. In contrast, adolescents in poor control reported that they were treated differently than their siblings, and family members were critical, distrustful, or indifferent about their diabetes management.

In attempting to understand the relationships between support and metabolic control, Hanson, Henggelar, and Burghen (1987c) postulated that parental support (based on the DFBC which focused on positive and negative responses of the parent in regard to the subject's treatment regime) indirectly influences metabolic control through regimen adherence. They also found that the age of the adolescent significantly predicted the level of support. As the age of the child increased the parental support decreased. In this same research, Hansen et al. (1987c) argued that chronic life stress had a direct link to metabolic control. In researching this they found that the impact of stress on metabolic control was buffered by social competence but not by social support. However, it was noted that social competence is best acquired in a supportive family.

In 1989, Hanson, Henggelar, Harris, Burghen, and Moore, found that good metabolic control was associated with high marital satisfaction and family adaptability/flexibility, and marginally associated with high family cohesion. These relations were especially strong with a shorter duration of illness. With longer durations of illness, the associations became weaker.

Burroughs, Pontious, and Santiago (1993) further extended Hanson's model by testing the family support components (the degree of positive and negative interactions) separately for each adherence variable (diet, glucose monitoring, insulin adjustment, hypoglycemia control, exercise, and foot care). The results were duplicated that the impact of support variables on metabolic control were

dependent upon an association with the adherence variables. In this study they found, as expected, that adolescents with good metabolic control had parents who supported their adherence to their treatment regimen with positive supportive behaviors. In contrast, those adolescents whose parents used nagging supportive behaviors had poor metabolic control. It was postulated that perhaps these adolescents did not want to deal with adherence particularly in front of their peers and were choosing to go along with the crowd and maintain self-esteem disregarding the negative consequence on their metabolic control. It was also suggested that some of these youths might be more successful at power struggles with their parents at the cost of good metabolic control. Additionally, they found that dietary adherence was most closely associated with metabolic control. One problem with this study is that parental support was measured with the DFBC measurement tool, which was not found to be reliable and valid with adolescents (Schafer et al. 1986).

In a later study by Seiffge-Krenke (1998), adolescents with diabetes and their parents (as compared to healthy adolescents and families) were found to have a family climate that was less cohesive but highly structured, organized, controlling, and achievement oriented. Additionally, family climate such as cohesion, expressiveness, and low conflict was not related to metabolic control. This finding was in contrast to the results reported by Hanson et al. (1989) where good metabolic control was related to high family relations and flexibility, especially when the illness was of shorter duration.

A study by Hanson, DeGuire, Schinkel, and Kolterman (1995) also found that adolescents with diabetes described their family climate as less cohesive and less stimulating than in families with a healthy adolescent. However, they concluded

that positive family relations (high family cohesion and low family conflict) did relate indirectly to good metabolic control through positive adherence behaviors. They also noted that higher levels of family-life stress were directly related to worse metabolic control. Additionally, they found that high levels of stress related indirectly to poor family relations, which then also related to poor metabolic control.

In a ten-year longitudinal study, Kovacs et al. (1992) found no relationship between baseline family support characteristics (open communication, conflict resolution, family loyalty and satisfaction and close familial relations) and later regimen adherence. It is possible that the type of family support characteristics need to reflect the changing developmental needs experienced throughout adolescence or that the measures were not accurately picking up perceived support related to conflicts. Jacobson et al. (1994) considered the developmental aspect and studied changes in family support (cohesion, conflict, expressiveness, and organization) as measured by the mother's support through the adolescent period. They found that adapting family support coupled with low conflict did protect the adolescent from poor control over the four years post diagnosis.

As the study by Jacobson et al. (1994) would suggest, conflict with parents is one factor contributing to adolescents achieving poorer metabolic control. The study by Miller-Johnson et al. (1994) supported this. They found that parent-child conflict contributed unique variance in predicting both poor adherence and metabolic control. They postulated that the parent-child conflict that often arises in the adolescent period may be responsible for some of the difficulties in diabetic health management.

In a different light, Bennett & Westera (1994) found that adolescents generally identified their families as the most supportive and influential in their lives, although a significant number of them identified frequent family arguments. In this particular study, the adolescents were able to explain that arguments with their parents did not mean they were unhappy or unsatisfied. They still described a happy home.

Communication was another aspect of family support studied as it related to adherence and good glycemic control. Studies by Wysocki (1993) and Bobrow, AvRuskin and Siller (1985) found that adolescents, in families where communication was commonly open and empathetic with good conflict resolution skills, demonstrated better adjustment and adherence to the treatment regimen. Hanna et al. (2003) also studied communication (amount and agreement with parents) and parental support (related to adolescent seeking and receiving parental help with diabetic management). They found a significant difference between adolescents seeking and receiving parental support for diabetic management where more parental support was received than was asked for by the adolescent. They also found that when there was less communication agreement, the adolescent suffered worse metabolic control. Good parent-adolescent communication was considered a facilitator of parental support to adolescents with diabetes. However, the more adolescents received support, the less they were able to engage in their own decision-making. The issue can further be compounded by unclear patterns of communicating illness-related issues between parents and adolescents as were found by Anderson and Coyne (1993).

Saucier (1984), found that good self-care management was associated with the interaction of the child's age, self-concept, or self-esteem and participation in

outside activities. Based on the fact that one's self-definition (self-esteem) is the reflection of the appraisals of significant others, Yarcheski, Mahon, and Yarcheski (1997) point out that social support is linked to self-esteem. It also would seem to follow that good social (parental) support is linked to good self-care management. Skinner and Hampson (1998) found that family support was a significant predictor of all self-management measures.

Hanson et al. (1989) found that the longer the patient had diabetes, the weaker the association between family relations (family cohesion) and good diabetic control became. Wysocki, Hough, Ward, and Green (1992) found that early adjustment of IDDM was predictive of later adolescent control. They also found that good family communication and conflict resolution skills were associated with better adherence and adjustment to IDDM. Families who were supportive early on in helping their child to achieve good metabolic control were less likely to negatively influence the normal developmental process of adolescence (Maddux, Roberts, Sledden, & Wright, 1986).

Hanson, Henggeler, Rodrigue, Burghen, and Murphy (1988), studied father-absent families, social support, adherence, and metabolic control. They found better adherence in the father absent group compared to a group of intact families but not better metabolic control. Although the social support characteristics seemed to vary between daughters and sons, it appeared that the loss of a father may have promoted more responsible and adult-like behavior in the adolescent.

Many studies on social support and glycemic control involved white middle class intact families. A few researchers looked at racial differences and found that although black adolescents had higher blood glucose levels compared to their

white counterparts, no relationship was found between the two groups and the qualitative aspects of social support (Delamater, Albrecht, Postellon & Gutai 1991; Hanson, Henggeler, & Burghen, 1987b). On the other hand, Davis et al. (2001) found an association between parental restrictiveness and black ethnicity, lower SES, and worse glycemic control.

Regimen Specific Support Behaviors.

Several studies looked at regimen-specific support behaviors. These behaviors included, encouraging glucose testing, helping with injections, and purchasing the proper nutritional foods. Looking at the frequency of these types of behaviors it was found that parental use of both encouraging and nagging types of behaviors were predictive of dietary adherence. The study by Schafer, Glasgow, McCaul, and Dreher (1983) found that criticism and nagging resulted in worse metabolic control where as no relationship was found between positive/encouraging behavior and metabolic control. The study by Burroughs et al. (1993) found that parents who used negative behaviors to facilitate adherence tended to have children with poorer metabolic control. However, it was shown that youths' dietary adherence was positively linked to a father's nagging support.

Hanson, DeGuire, et al. (1992) researched the contribution of both the qualitative family support characteristics (also based on the DFBC with limited reliability and validity with adolescents) with the more regimen-specific support behaviors on dietary adherence and psychological adaptation. They found high levels of regimen support and high levels of family support and flexibility predicted dietary adherence and general psychological adaptation. None of the measures predicted metabolic control.

Transfer of Diabetes Management Responsibility

The transfer of diabetic management responsibility from parent to adolescent is a necessary process for the adolescent to become a competent self-governing adult. However, several studies have shown that too early a transfer of diabetic management can lead to poor metabolic control (Allen, Tennen, McGrade, Afflect, & Ratzan, 1983; La Greca et al. 1990). It may also adversely affect parent-child relations and the child's self-concept (Giordano, Petrila, Banion, & Neuenkirchen, 1992). Follansbee (1989) found that children's readiness to assume self-care responsibility is affected by the following factors: the child's and parent's knowledge of diabetes, the child's cognitive development and age, the family environment, and the child's actual performance of diabetes-related tasks. Giordano et al. (1992) suggest that the transition be gradual with parent's continued involvement as the child/adolescent assumes more and more of the responsibility. Anderson et al. (1990) also found that it is very important that communication be clear when tasks are transferred.

Siblings and Peers

Considering an ecological perspective one must also recognize the potential influence of others in the social network such as siblings or peers. Hanson, Henggelar, et al. (1992) found that although there was a significant association between sibling conflict and the adolescent's adaptation to IDDM there was no significant association between sibling relationships and glycemic control. Related to conflict, Hanson, Henggelar, et al. (1992) found that adolescents who had closer, minimally conflicted relationships with siblings seemed to adapt better to their IDDM and to life in general.

As a function of their development, adolescents spend a majority of their time with peers. Next to parents, peers are the most influential and perhaps understudied group. La Greca and Skyler (1991) studied the support given from family and peers and found that although families offered more tangible and regimen specific support, peers offered emotional support (interpreted as acceptance). Varni, Babani, Wallander, Roe, and Frasier (1989) reported while "family social support is predictive of psychological adaptation in children" with IDDM, only youth's perception of support from their peers is "predictive of psychological adaptation" during adolescence (p. 9). In another study, La Greca et al. (1995) agreed that both parental and peer support were distinct and both were considered important to the adolescent.

Ellerton, Stewart, Ritchie, and Hirth (1996) also found that two sources of support, parents and peers, were particularly important to children and adolescents with a chronic illness. The subjects expressed a need for peer friendships. Although children with a chronic condition identified smaller sized social support networks and less support functions from non-family members they were overall satisfied with their support systems. It was also noted that older children were overall less satisfied with their support than were the younger children.

Developmental Aspects

Several researchers have identified that metabolic control especially seems to deteriorate in the older adolescent (Delahanty & Halford, 1993; DCCT, 1993; Grey, Cameron, & Thurber. 1991; White, 1990). Considering these findings, it would seem imperative to examine adolescent development.

In a more recent study by Dashiff and Bartolucci (2002) developmental attributes of the adolescent, more specifically behavioral, cognitive and emotional autonomy, were examined in relationship to metabolic control. It was recognized that although the process of autonomy development is not fully understood, adolescents' desire for autonomy often exceeded their ability to be autonomous. Cognitive autonomy referred to the "reasoning and understanding of self" in relationship to parent. "Self-governance, an aspect of cognitive autonomy is valued highly by adolescents"(p. 97). Behavioral autonomy refers to self-determined actions such as personal care, management of responsibilities, and initiative in activities. Behavioral autonomy is often the basis that parents use to give greater freedoms. Emotional autonomy refers to the adolescents separating from parents, by becoming less dependent and by conceptualizing them more realistically.

Dashiff and Bartolucci (2002) found that only one aspect of emotional autonomy was significantly associated with poor metabolic control. Daughters and adolescents in single parent families scored higher on the one aspect of the emotional autonomy scale that was used to signify a more limited relationship with the parent/s. These adolescents were more likely to perceive their parent/s as being less stable and less consistent. This would suggest that higher emotional autonomy (in part, based on a perception of the parent/s) in early adolescence, especially in daughters and those in single-parent-homes, may be associated with poorer self-care management and poorer metabolic control.

Normally it would be expected that each aspect of autonomy would increase with age, however, no relationship was found in the Dashiff and Bartolucci (2002) study. This may be attributed to the small age range studied (11–15 years).

However, there was a relationship between pubertal age and autonomy. This finding concurred with earlier studies that parents may grant more freedom based on more mature physical cues ("looking older"). The concern here is that excessive behavioral autonomy in the adolescent who may not be cognitively or emotionally ready may result in poor self-care management and poor decision making. In summary, it appears that pubertal stage, family structure, perception of parents and gender may significantly affect the development of autonomy and ultimately metabolic control in those adolescents with Type1 diabetes.

Perceived Support

In attempting to understand how support relates to promoting health, it is important to note that supportive behavior is often a function of not only who is available to be supportive, but also how the support-receivers perceive the support (support appraisals). There needs to be a match between support given and how the support received is perceived. This is evidenced in the highly consistent findings that it is the perception of social support that is most closely related to health outcomes (Cohen et al, 2000; Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane,1998; La Greca et al, 1995; Rohrle & Sommer, 1994). Hanna & Guthrie (2001) did a qualitative study on parent's and adolescent's perceptions of the helpful and non-helpful dimensions of support related to the adolescent assuming diabetic management. They identified that both parents and adolescents described "directive guidance" and "tangible assistance" as both helpful and nonhelpful. The helpfulness of these dimensions depended on the degree of directness and the perceived need for help.

Weinger et al. (2001) studied the adolescent's perception of diabetes-related parental conflict and support. They found that "parental worry" which

manifested in "intrusive behaviors," "parental blaming" resulting from a "lack of understanding," and differences in "future" versus "present" focus between parent and adolescent were major areas of conflict (p. 334). This study suggests the need for greater understanding of the conflicts and more dialogue between parents and adolescents as it relates to diabetic health care management.

Parenting Styles

Supportive parents are seen as warm, firm, close and nurturing. They are involved in the adolescent's life by attempting to decrease exposure to risks and encouraging protective factors. They reinforce positive family values and are often described as "authoritative" in their parenting style (Glasgow et al. 1997).

Authoritative parents are seen as loving and democratic. They encourage adolescent autonomy by expecting and reinforcing appropriate behavior, maturity, and responsible decision-making. They encourage open communication and value the rights of both parents and the adolescent (Baumrind, 1991; Glasgow et al. 1997).

Supportive parents contribute to positive development and maturation of their adolescent by being both separate from them and still connected to them. By the nature of their developmental tasks, adolescents need to emancipate themselves from their parents and form their own identities. Supportive parents facilitate their adolescent's emerging autonomy by staying involved, being firm and loving, and effectively negotiating rules, i.e. reflecting the authoritative parent (Baumrind, 1991; Glasgow et al. 1997).

Baumrind (1971, 1991) identified three styles of parenting after studying parents interacting with their children. She used the construct of parenting style to capture normal variations in the parent's attempt to control and socialize their

children. She categorized parent's interactions with their children using a typology based on two stylistic dimensions of parenting: warmth/responsiveness and control. Baumrind defined "control" as employing discipline as well as providing structure, setting limits, and communicating expectations for competent, age-appropriate behavior (Cowan, Powell, & Cowan, 1998).

> Baumrind describes parents who are 'warm and responsive' to their children and who provide a structure for their learning, set limits when their behavior threatens to go out of control, and set explicit standards for competent behavior, as *authoritative*. Parents who are warm and responsive but exert little control and make few maturity demands are described as *permissive*. Parents who are controlling in a cold, unresponsive way are described *authoritarian* (p. 6).

Building on Baumrind's work, Maccoby & Martin (1983) further clarified that parenting style captured two important dimensions: parental responsiveness (warmth and supportiveness) and parental demandingness (behavioral control). In categorizing parents according to how high or low they were on parental demandingness and responsiveness, Maccoby & Martin (1983) added a fourth typology, that of being uninvolved or neglectful. Parents who are low in warmth and control are considered more "neglectful" in their style of parenting. Overall, adolescents whose parents have an authoritative parenting style show higher levels of competence than children raised by parents using either the permissive or authoritarian styles (Baumrind, 1991; Dornbush, Ritter, Leiderman, Roberts, & Fraleigh, 1987).

In a recent article on parental involvement and adolescents with Insulin Dependant Diabetes Mellitus, Hanna et al. (2003) suggest studying family

functioning in terms of parenting styles to further delineate communication issues between parents and adolescents. In addressing family conflict and diabetes management in youth, Anderson (2004) also studied the link, based on recent research reviews, of the relationship of different parenting styles to glycemic control and adherence. She concedes that prior research on diabetes and general parenting characteristics such as parental warmth and reasonable demands on child's behavior (reflective of authoritative parenting) were related to better adherence and metabolic control. More research is needed in order to validate these preliminary findings and to learn how to assist parents to better negotiate their role in diabetes management with their child.

The impact of parenting style has not been studied in terms of how it relates to a child's sense of self or quality of life. Parents should be warm and responsive to their adolescent's needs, especially health care needs, and provide appropriate structure and guidance. They need to encourage adolescent autonomy by expecting and reinforcing appropriate behavior, maturity, and responsible decision-making. When this occurs through authoritative parenting practices, youth of all ages may experience more support, less stress, and in turn, feel better about themselves and their quality of life.

Quality of Life

Quality of life is increasingly becoming more recognized as an important factor in outcomes assessment of individuals with chronic illness (Delamater, 2000). Hence, it is important to consider quality of life issues in adolescents with diabetes. Diabetes imposes considerable demands on the adolescent that may interfere with his or her ability to negotiate important developmental tasks and achieve good psychosocial adjustment. This is especially true as the expectations

placed on the adolescent to follow strict insulin regimens in order to attain and maintain optimal levels of glycemic control and reduce the risks of health complications have intensified. By studying the quality of life, one can determine the impact of a chronic illness such as diabetes on one's physical, psychological, and social functioning (Delamater, 2000).

In addition to achieving good metabolic control, it is also an important goal to ensure that the adolescent develop optimally in all areas of his or her life including psychological, social, academic, and physical (Delamater, 2000). Because these areas are greatly influenced by family relationships, researchers need to include these aspects when studying adolescents with diabetes.

In a review of the literature, Delamater (2000) noted that quality of life, is "an important yet understudied issue in adolescents with diabetes. Reviews of research findings indicate that psychosocial functioning and quality of life may be adversely affected by diabetes"(p.42). Because of its importance as an outcome, Delamater stresses that quality of life should be routinely included in future research.

A study by Grey et al. (1998), found that adolescents with diabetes generally perceived their quality of life as good with diabetes having a moderate impact on their quality of life. They also found their families to be "warm and caring, but providing less guidance and control than average adolescents." Against expectations and in contrast to previous findings family functioning as measured by adaptability and cohesion, or warmth and caring was not associated with quality of life. However, the perception of having families that provided more guidance and control was associated with better metabolic control (Schafer et al. 1986). These findings would suggest that more research is needed to clarify

aspects of the parent-adolescent relationship that can impact the adolescent's quality of life.

Summary

In summary, adolescents today live in a culture that exposes them to many health-compromising risks. Family/parental support is crucial for both healthy and ill children and adolescents. Parents play a significant role in the development of health behaviors. Several studies have shown the positive correlations of parental support and healthier outcomes for adolescents (Benson, 1997; Resnick, et al. 1997; Scales & Leffert, 1999).

The same is true for adolescents suffering from a chronic illness such as diabetes. The majority of studies that focused on family characteristics in which the parents were warm, caring, involved, and possessing good, open family communication were more likely to have adolescents who were better adjusted and had better compliance and in some cases better metabolic control (Anderson, et al. 1981; Hanson et al. 1995; La Greca et al. 1995; Wysocki et al. 1992). It has also been shown that good parental support has been linked with positive self-concept, but that in spite of a good self-concept, some adolescents still followed their diet less closely and therefore had poorer metabolic control (Burroughs et al. 1993). Research has also shown that communication about responsibility for regimen tasks, especially during early adolescence when responsibility is being shifted from parent to child, and ongoing involvement of parents is particularly critical if good adherence is to be achieved (Anderson et al. 1990). Additionally, as the diagnosis of Type I diabetes is a stressor for children and adolescents, research should focus on both physiologic (metabolic) and psychologic adaptation (Grey & Thurber, 1991).

Much can be gleamed from this review of the literature. Several factors (family environment, cohesion, self-concept, supportive parents, low conflict, regimen-specific support behaviors, communication patterns, dietary adherence, ongoing parent involvement, life-stressors, and coping patterns) have been associated with glycemic control, positively and negatively. The process of achieving good glycemic control is complex and it becomes inherent to look at the interrelatedness of the above components in addition to exploring new factors when looking at social support and its impact on diabetic health management.

The 1993 landmark study by the DCCT demonstrated that achieving good glycemic control could deter the common complications associated with IDDM for many years. In order to help adolescents with Type 1 diabetes achieve good metabolic control and stave off complications, health care providers need to be aware of these factors as they research, guide, educate, and collaborate with these families.

CHAPTER 3

METHODOLOGY

This chapter will describe the methods used to carry out the study. First the design will be discussed, followed by description of the research participants, instrumentation, procedures used, and data analysis.

Design

This cross-sectional quantitative study explored the nature of support that enables adolescents to most effectively manage their diabetic care. This causal comparative study was carried out in a natural setting. The unit of analysis was the adolescent between 12 and 18 years of age. Adolescents were targeted if they were in the designated age range, had been diagnosed with insulin dependent diabetes for at least one year, met the criteria, and attended a large pediatric endocrinology clinic in West Michigan.

Research Participants

The subjects of this study were adolescents between the ages of 12 and 18 years, diagnosed with IDDM/Type 1 diabetes who saw any one of the pediatric endocrinologists at the designated clinic. Criteria for inclusion in the study included 1) age 12 through 18 years, 2) living with a parent, 3) ability to speak or read English, 4) living with a diagnosis of diabetes for at least one year, 5) having a diabetes regimen that included insulin injections or the use of an insulin pump, glucose monitoring, meal planning and exercise, and 6) not having a diagnosis of any mental health issues. The first 123 adolescents meeting the criteria were asked to participate in the study. Permission to conduct this study was granted from Michigan State University Human Subject Review Committee, the Human

Subjects Review Committee for the associated health care institution and the Administrative Office of the clinic involved.

One hundred two adolescents (ages: 12 to 18 years) with Type 1 diabetes participated in the study. Of the 123 subjects approached, eight declined or changed their minds stating time issues, eight were found ineligible (after closer scrutiny), one withdrew after an unexpected death in the immediate family and four failed to return the questionnaires. The participating adolescents had been diagnosed with Type 1 diabetes longer than one year, had no significant mental health issues, lived with at least one parent and were on a treatment regimen that included insulin via injections or the use of an insulin pump.

The adolescents were asked to provide information on their background and current family situation. These variables included age, sex, ethnic identification (African-American, Asian-American, Hispanic-American, Caucasian and other), family structure (two natural parents, single parent, stepfamily, other), and the amount of education completed by each parent residing in the home (coded as less than college completion or college completion and higher). These variables were included as the scores on parenting practices and the dependent variables may vary according to the adolescent's age, sex, ethnicity, parental education and family structure (Lamborn et. al., 1991).

There was a fairly equal number of males and females (Table 1). The majority of the participants were Caucasian. The category of "other" was marked when an adolescent was a blend of two or more ethnic groups. Ages ranged from 12 to 18 years with age 15 as the mean and median (see Table 2). Average age at diagnosis was 7.69 years. Adolescents reported missing an average of 3.3 days of school in the last year as a result of their diabetes.

Table 1

Description of Categorical Demographic Variables (N=102)

Variable		n	%
Gender	Male	52	51
	Female	50	49
Grade	6	4	3.9
	7	11	10.8
	8	13	12.7
	9	16	15.7
	10	22	21.6
	11	17	16.7
	12	16	15.7
	1 yr. college	1	1.0
	Missing	2	2.0
Ethnicity	Caucasian	91	89.2
	Black/African American	3	2.9
	Hispanic	2	2.0
	Asian American	1	1.0
	Other	5	4.9

Table 2

Description of Quantitative Demographic Variables (N=102)

Variable	Median	Mean	SD	Range
Age	15	15	1.67	12 - 18
Age at diagnosis (yrs)	8	7.69	3.55	1 - 15
Days of school missed	2.5	3.3	4.48	0 - 30

Table 3

Family Structure and Education Levels

Variable	n	%
Family Structure		
Two natural parents	70	68.6
Single/divorced parent	14	13.7
Step-family	9	8.8
Other	9	8.8
Father's Education Completed		
High-school or less	52	51.0
College of more	45	44.1
Missing	5	4.9
Mother's Education Completed		
High-school or less	48	47.1
College or more	54	54.9

Regarding family structure, the majority of adolescents lived with two natural parents (Table 3). A small percentage of adolescents marked "other" for family structure. This "other" category seemed to reflect adolescents who had two involved natural parents who were divorced and also had step families. Educational levels between mothers and fathers appeared comparable except slightly more mothers completed college or more.

Data Collection Procedures

The staff research nurse at the pediatric endocrinology clinic helped determine the eligibility of the adolescents meeting the criteria. Once eligibility was established the research nurses approached the first 123 adolescents and their families when they arrived for their scheduled endocrinologist visit. First, the parents and adolescent were asked for their willingness to participate. The adolescents and parents who expressed interest and a willingness to be involved were asked to sign an informed consent and assent form detailing the nature of the study, an approximate length of time required to complete the four surveys, and contact information for the investigator. Copies of the consent/assent form were provided for participants to take home, in accordance with the guidelines of the Michigan State Committee for the Protection of Human Subjects.

For the purpose of anonymity the recruiting research nurse documented the name of the participating adolescent on a form identifying them with an identification (ID) number. While waiting, the adolescents were given the surveys and return envelopes only marked by this ID number. The nurse or physician then documented the patient's last four HgbA1c values on a corresponding sheet with the patient's initials and ID number. When the four surveys were completed at the clinic the adolescent was instructed to put them in

a sealed envelope and return them to the specified collection box. No one in the office was able to see the responses of the adolescent. For the majority of adolescents who needed to complete their surveys at home, a pre-addressed stamped envelope was provided. Several adolescents did receive phone calls or mailings reminding them to return their completed surveys. Each participant was mailed $10 upon the receipt of their completed questionnaires and was included in the drawing for four $50 gift certificates (awarded at the completion of data collection) as an incentive to encourage adolescents to submit completed questionnaires.

Instrumentation

In addition to the demographic variables, the variables of interest for this study included the two independent variables--parenting styles and perceived parental support--and the three outcome or dependent variables. The dependent variables included the HgbA1c laboratory values indicating glycemic control, adherence to treatment plan measures, and measures reflecting the adolescents' perceived quality of life.

The following questionnaires were chosen to specifically obtain the adolescent's perspective. This is justified on several grounds. First, parental and adolescent reports of adherence behaviors have been highly correlated (Miller-Johnson et al. 1994). Secondly, how adolescents interpret their home environment is crucial to understanding how they react or respond to it (Cohen et al. 2000; Glasgow et al. 1997; Pierce et al. 1996). Additionally, in terms of parenting, Bronfenbrenner (1979) has argued that youths' perceptions of their parent's behavior may be as important as the parent's actual parenting practices. It has also been reported that parents often overstate their supportive behaviors

and that adolescents often report less supportive behaviors than do their parents. Also the perspectives between mother and father differ in terms of portraying the family climate (Seiffge-Krenke, 1998).

Perceived Parental Support

Perceived parental support was assessed using the Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (Hanna et al. 2004). This scale was specifically developed to facilitate research on parental support for adolescent's development of diabetes management autonomy. The scale consists of items identifying frequency of enacted support and perceived helpfulness. It also measured support dimensions of guidance (behaviors to improve performance) and nondirective support (behaviors expressing caring). The initial scale started with 40 items and after content validity indexes, item analyses, and factor analyses, several items were deleted, leaving a total of four items. These items were scored using a 5-point Likert-scale eliciting perception of parental enacted support (0=none of the time to 4=all of the time) and perceived helpfulness (0=not at all to 4=very helpful). The scale provided a sum of responses for the frequency of enacted support and a sum of responses for perceived helpfulness of support. As suggested by the author, the perceived parental support score reflected the combination of support scores obtained from the frequency responses of enacted support multiplied by the perceived helpfulness responses of support (N. Darling, personal communication, March, 16, 2006). Only one subject left two items blank and these values were imputed based on the mean of other scores provided for that section. According to Hanna et al. (2004), the instrument's internal consistency reliability coefficients ranged from 0.77 to 0.80. Construct validity was supported by the relation of this scale with other

measures of parental support such as the Support Subscale of the DFBC (Schafer et al. 1986) and Guidance/Control and Total Scale of the DFBC (Hanna et al. 2004; McKelvey et al. 1993).

Parenting Styles

Parenting style has most often been identified by characterizing the parenting environment along two continuous dimensions: demandingness and responsiveness. These dimensions were based on the previous research of Baumrind (1971, 1991) and Maccoby & Martin (1983). One problem noted with earlier parenting style instruments was that they did not distinguish between parenting style and parenting practices. Parenting style refers to the "overall emotional climate in which particular parent-child interactions occur;" whereas parenting practices are "directed towards particular goals" such as "encouraging academic achievement" (Darling & Toyokawa, 1997, p. 2). The PSI-I was developed to evaluate parenting style independent of parenting practice as described by Darling and Steinberg (1993).

The PSI-I had been further revised to improve internal consistency and variability of items, and to decrease bias. Additionally, to better assess dimensions of parenting style, Darling added a third subscale of psychological autonomy-granting. Psychological autonomy-granting relates to the level of behavioral as well as psychological control attempts of the parent(s) over the adolescent (Darling, n. d.). The revised version is called the PSI-II (Darling & Toyokawa, 1997).

In this study, parenting styles were measured using the Parenting Style Index–II [PSI-II] (Darling & Toyokawa, 1997). The PSI-II consists of the three subscales (responsiveness, autonomy-granting, and demandingness) with five

items each. According to Darling and Toyokawa, each subscale showed acceptable alpha levels (responsiveness - .74, autonomy-granting - .75, and demandingness -.72). Inter-correlations were also reported (Responsiveness: Demandingness – R=34; Responsiveness: Autonomy-Granting – R=.46; and Demandingness: Autonomy-Granting – R= -.11). Although there may be some concern regarding the interrelationships between responsiveness and demandingness, or responsiveness and autonomy-granting, this is consistent with the interrelationships found in other studies and may reflect the adolescents' perception of a link between parental rule setting and emotional attachment (Darling & Toyokawa, 1997). Validity was also measured using correlation coefficients to show the relationship between positive parenting and adolescent outcomes, parenting practices and perceived authority. These values were in the expected magnitude and direction (Darling & Toyokawa, 1997).

As suggested by the author (N. Darling, personal communication, March, 16, 2006) and consistent with the literature (Darling & Toyokawa, 1997; Maccoby & Martin, 1983) two of the three subscales (responsiveness and demandingness) were used to categorize parenting into four styles of parenting (authoritative, authoritarian, permissive and neglectful). There were no missing values except for responses on fathers when the father was not involved in the adolescents life (n = 7). The measures for two parent households were averaged. According to Baumrind (1991), there is significant convergence between the adolescents' perceived mothers' and fathers' ratings. The data in this study supported this as well.

For thoroughness, parenting style was analyzed three different ways as suggested in the literature or in a personal communication with the author. First,

four parenting styles or categories were defined by using a mean-split procedure (N. Darling, personal communication, March, 16, 2006; Weis & Schwartz, 1996). Scores on the demandingness and responsiveness subscales were used to assign parents to one of four parenting style groups. Once the mean was obtained (mean = 19), parents were placed into one of the parenting style groups based on whether they were above or below the mean (see Table 4). With this technique there was a fairly equal distribution of subjects across each of the four parenting styles. No subjects were excluded.

Table 4

Mean-Split Parenting Style Grouping (N=102)

Variables	Demandingness	
	Above the mean	Below the mean
Responsiveness		
Above the mean	Authoritative (n=23)	Permissive (n=25)
Below the mean	Authoritarian (n=27)	Neglectful (n= 27)

Secondly, the method of trichotomizing the sample was used in order to ensure distinct categories of parenting styles (Lamborn et al. 1991; Steinberg et al. 1994). In this method, the responses on each of the subscales were trichotomized. Only subjects falling in the upper or lower tertiles were used in the analyses. This technique caused the exclusion of several subjects. Authoritative parents scored in the upper tertiles for both demandingness and responsiveness; authoritarian parents scored in the top tertile for demandingness, but the bottom tertile for

responsiveness; permissive parents were high on responsiveness but low in demandingness; and the neglectful parents were low in both demandingness and responsiveness. Table 5 reflects the distribution of subjects according to each method.

Table 5

Parenting Style Groupings According to Method of Analysis

Variables	Mean-Split	Tertile-Split	K-means Cluster
Authoritative			
n	23	17	37
%	22.5	16.7	36
Authoritarian			
n	27	10	16
%	26.5	9.8	16
Permissive			
n	25	9	45
%	24,5	8.8	44
Neglectful			
n	27	18	4
%	26.5	17.6	4
Total N	102	54	102

The third method of analyzing parenting style involved the K-means cluster analysis. With this method the ideal parent types were entered to see where the study parents fell. Based on the responsiveness and demandingness scores, parenting styles were grouped to display small within-cluster variations, and large between-cluster variations (Kachigan, 1991). Again, parenting styles which reflected high demandingness and high responsiveness scores were used to

create the authoritative group, parenting styles which reflected low responsiveness but high demandingness were used to create the authoritarian group, parenting styles which reflected high responsiveness but low demandingness were used to create the permissive group, and parenting styles which reflected low responsiveness and low demandingness were used to create the neglectful group. Table 6 presents the responsiveness and demandingness means and standard deviations that were used to create each of the four parenting cluster groups.

Table 6

K-Means Cluster Groups

Variables	n	Responsiveness		Demandingness	
		Mean	SD	Mean	SD
Authoritative	37	21.99	1.99	21.18	1.83
Authoritarian	16	14.91	3.07	21.59	1.17
Permissive	45	18.63	1.68	17.30	1.72
Neglectful	4	12.75	3.01	14.88	3.33

Adherence

Adherence was measured using the Diabetic Behavior Rating Scale (DBRS), (Cook et al. 2001; McNabb et al. 1994). The DBRS, a more recent version of the Children's Diabetic Inventory, roughly assesses the degree of responsibility assumed by the adolescent related to 39 diabetes self-management behaviors and the frequency with which these are performed. These behaviors include daily

prevention activities, activities related to modification of the diabetes care plan, intervention behaviors such as those related to illness, and activities to maintain diabetic care supplies. Additionally, these behaviors assess the four areas of adherence: diet, exercise, glucose testing, and insulin administration that are considered important by the American Diabetes Association. Both responsibility behaviors and their frequency are rated on a 5-point scale (5=adolescent totally responsible to 1=parent totally responsible; and 5=always to 1=never). Cronbach's alpha was reported to be 0.86 for the behavioral frequency items and 0.94 for the degree of responsibility items (McNabb et al. 1994). Content validity was earlier assessed by a panel of experts. Construct validity was supported from the findings of children's overall level of diabetes self-care responsibility behaviors significantly correlating with age (McNabb et al. 1994). In this current study, as suggested by one of the authors, adherence was based on the sum of frequencies in which adherence behaviors were performed (S. Cook, personal communication, January, 19, 2006). Missing values were imputed based on mean scores from items in the same section.

Metabolic Control

Metabolic control is routinely measured during clinic visits by obtaining a blood sample and measuring the adolescent's hemoglobin A1c (HgbA1c). It is a value that reflects the level of serum glucose over the preceding six to eight weeks as the glucose molecule attaches itself to the red blood cell for the life of the red blood cell. It is considered the best indicator of control during the preceding two to three months. To control for skewed values that may occur during the honeymoon phase (defined as the period in which doses of insulin are < 0.5 units/kg/day, post diagnosis), metabolic control was determined based on

the average of the last four HgbA1cs over the last year or since the adolescent came out of the honeymoon phase. The patient's last four documented values were recorded from the adolescent's medical record by the nurse or physician. These values were then averaged by the investigator to determine the average HgbA1c. The American Diabetes Association (2006) recommends the goal for HgbA1c values to be in the range of 6% - 7%.

Quality of Life

Quality of life was measured by the Diabetes Quality of Life for Youth [DQOLY] (Ingersoll & Marrero, 1991). This instrument is an adaptation of the Diabetes Quality of Life measure that was developed specifically to assess the psychosocial impact of the intense diabetic treatment regimens for participants in the DCCT. Items of little relevance to adolescents and children were omitted or modified. A panel of pediatric diabetic experts verified the content validity of the resulting items. The revised instrument with a 5-point Likert-scale contains 3 subscales. The first is a 26-item Diabetes Impact Scale that rates the impact of diabetes on life from 1 (no impact) to 5 (always affected). The second is a 13-item Disease-Related Worries Scale that rates worries related to diabetes from 1 (never worried) to 5 (always worried). The third is a 17-item Diabetes Life Satisfaction Scale that rates satisfaction with diabetes from 1(very satisfied) to 5 (never satisfied). Following the three subscales, the authors included a general rating scale of overall health (utilizing a 4-point scale, 1=poor to 4=excellent). In this study, quality of life was analyzed using the summation of each of these sub categories (impact, worry and satisfaction). Missing values were imputed based on mean scores from items in the same sub category. Cronbach's alpha scores of the Diabetes Impact Scale, the Disease-Related Worries Scale, and the Diabetic

Life Satisfaction Scale were reported to be 0.83, 0.82, and 0.85 respectively (Ingersoll & Marrero, 1991).

Data Analysis

Data analyses began with descriptive statistics to summarize the data. Since most of the data was ordinal in nature, the mean, standard deviation, and range were appropriate. Cross-tabulations assisted with organizing the data and provided a beginning look at the relationships among the variables.

Perceived Parental Support

To first investigate the relationships between the adolescent's perceived level of parental support and the dependent variables (adherence, metabolic control and quality of life) correlational analyses were conducted. Multiple regression analyses were then performed to evaluate the associations between the independent variable (perceived parental support) and the dependent variables (adherence, metabolic control and quality of life).

Parenting Styles

Since the data related to parenting styles was categorical, *t*-tests analyses and analyses of variance (ANOVA's) were performed to evaluate the differences between parenting style groups on the dependent variables (adherence, metabolic control, and quality of life). To determine if assumptions for statistical tests were met, Levene's Tests for Equality of Variances were run and when appropriate, non-parametric analyses were also completed. Multiple regression analyses were also performed to evaluate the associations between the independent variable (parenting style) and the dependent variables (adherence, metabolic control, and quality of life).

Summary

This chapter has explained the methods used in this quantitative analysis to study the relationships and differences between parental support, parenting styles and how the adolescent manages his or her diabetic health care. The next chapter will present the results of this quantitative analysis using these methods.

CHAPTER 4

RESULTS

The overall purpose of this study was to investigate the relationships of perceived parental support and differing parenting styles to adherence to diabetic health management, metabolic control and perceived quality of life for adolescents aged 12 to 18, diagnosed with insulin dependent diabetes. The chapter is organized by addressing each of the 12 research questions and the relevant null hypotheses.

Correlations were calculated to look for relationships between the two independent variables, perceived parental support and parenting style, and between the three subcategories of the parenting style inventory: responsiveness, demandingness, and autonomy-granting. A significant relationship was found between perceived parental support and two of the parenting style subscales; autonomy-granting subscale ($r = .267$, $p < 0.01$), and responsiveness subscale ($r = .433$, $p = .000$). (Note: analyses are reported as 2 tailed). Parental support was only mildly correlated with demandingness ($r = .188$, $p = .058$), although not significantly. A significant relationship was also noted between the responsiveness subscale and the autonomy-granting subscale of the parenting style inventory ($r = .587$, $p < 0.01$). The latter is consistent with what the researchers found in the development of the PSI-II (Darling & Toyokawa, 1997). The autonomy-granting subscale was not used in this analysis.

Correlations were also calculated between adherence and metabolic control (HgbA1c). In this sample, adherence and metabolic control were not significantly correlated ($r = .099$, $p = .322$).

Perceived Parental Support

The first three research questions are related to the research objective to investigate the relationship between levels of perceived parental support and adolescents' adherence measures, metabolic control and perceived quality of life. The first research question addressed perceived parental support and adolescents' adherence measures. Is there a relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan? The second and third research questions are similar but are investigating the relationships between perceived parental support and metabolic control and perceived quality of life respectively. These questions are answered by testing the following null hypotheses:

HO 1 There is no relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan.

HO 2 There is no relationship between adolescents' perceived level of parental support and their metabolic control.

HO 3 There is no relationship between adolescents' perceived level of parental support and their perceived quality of life.

Spearman's rho correlation coefficients were calculated to determine relationships for each of the null hypotheses (Table 7). A significant relationship was found between the adolescent's perceived level of parental support and adherence to a prescribed treatment plan ($r_2 = .3.75$, $p = .000$). Null hypothesis HO 1 was therefore rejected and research question 1 was answered affirmatively; "There is a relationship between adolescents' perceived level of parental support and adherence to a prescribed treatment plan." As the perceived level of parental

support increased so did the adolescent's adherence to a prescribed treatment plan.

No significant relationship was found between perceived parental support and metabolic control (r_2 = -.146, p = .144). However, a negative trend in the relationship was noted. Consequently, null hypothesis HO 2 was accepted and research question 2 was answered negatively; "There is no relationship between adolescents' perceived level of parental support and their metabolic control."

The third research question, "Is there a relationship between adolescents' perceived level of parental support and their perceived quality of life?" was analyzed using the three subscales for quality of life. First, a relationship was explored between perceived parental support and the impact of diabetes subscale. Quality of life, as assessed through the impact of diabetes subscale, did not show a relationship with parental support (r_2 = -.101, p = .313) [Table 7]. Also no relationship was found between the quality of life-worries about diabetes subscale and parental support (r_2 = -.033, p = .741).

On the other hand, the third subscale of satisfaction with life showed significant results. Even though, the analyses of parental support and the satisfaction subscale for quality of life demonstrated a significant relationship (r_2 = .233, $p < .05$), a closer look at the data, suggested re-analysis. The scatter plot revealed two influential outlying observations. In reviewing the raw data of these two subjects, it was judged that the responses for the quality of life satisfaction subscale were coded uncharacteristic to the responses of the other two subscales (impact and worry). Lower scores on the impact and worry sub-scales of 1 through 5 (1 being low and 5 being high) typically reflect better scores (less impact, less worry), whereas, lower scores on the satisfaction scale indicate

Table 7

Spearman's rho Correlation Coefficient Values (N=102)

Variables	Perceived Parental Support	
	r_2	*p*-
Adherence	.375	.000**
Average HgbA1c	-.146	.144
Quality of Life		
Impact	-.101	.313
Worry	-.033	.741
Satisfaction	.233	.018*

*$p < 0.05$
**$p < 0.01$

negative satisfaction. For these two subjects, impact scores and worry scores were typically scored low (mostly ones and twos) indicating less impact of diabetes and less worries. These two subjects also rated their overall health as good or excellent. In contrast, on the satisfaction scale these two subjects scored their satisfaction as mostly ones (very unsatisfied) or somewhat unsatisfied which appears uncharacteristic compared to the responses on the other two subscales. The conclusion of the researcher was that these two subjects incorrectly scored their responses. Therefore, the analysis was rerun excluding these outliers. Minus the two outliers, there was a significant relationship at $p < .01$ ($r_s = .278$) between perceived level of parental support and perceived quality of life based on satisfaction scores. Null Hypothesis HO 3 was rejected and research question 3 was answered affirmatively; "There is a relationship

between adolescents' perceived level of parental support and their perceived quality of life." Descriptive statistics for quality of life are presented in Table 8.

Table 8

Description of Quality of Life

Variable	Mean	SD	Possible Range	Sample
Quality of Life				
Impact	49.61	12.11	23-115	27-90
Worry	20.89	8.72	11-55	11-49
Satisfaction	64.41	12.18	17-85	18-85
Health Rating	3.06	.76	1-4	1-4

A multiple regression was run to determine if the independent variable of perceived parental support would predict metabolic control, adherence, or quality of life. The demographic variables of gender, age, grade, ethnicity, family structure, and mother's and father's educational level were also entered into the equation. The only variable to demonstrate a level of significance was adherence (Multiple R = .414; R^2 = .171; $p < .01$). Approximately 17% of the variation in adherence was explained by perceived parental support.

Parenting Styles

The last nine research questions are related to the research objective to investigate differences in adherence measures, metabolic control and perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have

authoritarian, permissive or neglectful parenting styles. Analyses of the research questions pursuant to this objective involved *t*-test analyses and ANOVA's. The *t*-test analyses using both the mean-split technique and the tertile-split technique demonstrated similar results. *T*-test analyses and the ANOVA used in the K-means cluster analyses resulted in additional findings. Differences in parenting styles as they relate to adherence measures, metabolic control and quality of life will be addressed separately.

Adherence

Research questions 4, 5, and 6 are concerned with differences in adherence measures between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive or neglectful parenting styles. These questions are answered by testing the following null hypotheses:

HO 4 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HO 5 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HO 6 There is no difference in adherence between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

After determining equality of variances, *t*-test analyses were performed to test these null hypotheses. A significant difference was found in adherence measures (based on frequencies) between adolescents who perceived their

parents to have authoritative parenting styles and adolescents who perceived their parents to have authoritarian, permissive or neglectful parenting styles.

The mean-split technique resulted in a significant difference being found only between adolescents who perceived their parents to have authoritarian and neglectful parenting styles compared to authoritative parenting styles. The means for the analysis are presented in Table 9 and the *t* values are presented in Table 10. However, a significant difference was found for adolescents who perceive their parents to have authoritative parenting styles compared to adolescents who perceived their parents to have permissive or neglectful parenting styles using the tertile-split technique (Tables 11 & 12).

Similar results were found using the K-means cluster technique. The K-means cluster analysis groups are described in Table 13. Using the K-means cluster groupings, *t*-tests showed a significant difference in adherence means between the authoritative parenting style group and the authoritarian, permissive and neglectful parenting style groups (Table 14). The one-way ANOVA resulted in similar findings. A significant difference was found in adherence between the different parenting style groups (Table 15).

Although the ANOVA showed a significant difference between parenting style groups in terms of adherence, it did not specify in which groups the differences were found. To help determine which groups demonstrated the differences, a post hoc analysis was run using the Least Significant Difference (LSD) analysis (Table16). The LSD analysis also demonstrated a significant difference in adherence means between the authoritative parenting style group and the authoritarian, permissive, and neglectful parenting style groups.

Null hypotheses HO 4, HO 5, and HO 6 were rejected and research questions 4, 5, and 6 were answered affirmatively; (4) "Adolescents who perceive their parents to have authoritative parenting styles have better adherence to their prescribed treatment plan than adolescents who perceive their parents to have authoritarian parenting styles," (5) "Adolescents who perceive their parents to have authoritative parenting styles have better adherence to their prescribed treatment plan than adolescents who perceive their parents to have permissive parenting styles," and (6) "Adolescents who perceive their parents to have authoritative parenting styles have better adherence to their prescribed treatment plan than adolescents who perceive their parents to have neglectful parenting styles."

Table 9

Mean-Split Mean Comparisons (N=102)

Variables	Authoritative (n=23)		Authoritarian (n=27)		Permissive (n=25)		Neglectful (n=27)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Adherence								
Frequency	3.82	.40	3.56	.45	3.72	.38	3.44	.45
Responsibility	2.43	.62	2.13	.70	2.48	.65	2.21	.62
Average HgbA1c	8.15	1.04	8.61	1.23	8.49	1.22	8.32	.89
Quality of Life								
Impact	45.83	10.34	53.93	16.74	47.72	10.34	50.26	9.19
Worry	18.65	7.37	23.63	10.96	18.64	7.37	22.15	7.56
Satisfaction	67.09	17.22	61.79	11.05	66.52	10.37	62.85	9.15

Table 10

Mean-Split t-test (N=102)

Variables	Authoritative/Authoritarian		Authoritative/Permissive		Authoritative/Neglectful	
	t	*p*	*t*	*p*	*t*	*p*
Adherence						
Frequency	2.085	.042*	.863	.393	3.119	.003**
Responsibility	1.614	.113	-.253	.802	1.237	.222
Average HgbA1c	-1.393	.170	-1.039	.304	-.617	.540
Quality of Life						
Impact	-2.015	.042*	-.669	.507	-1.605	.115
Worry	-1.846	.071	.006	.996	-1.649	.106
Satisfaction	1.326	.191	.139	.890	1.059	.297

* $p < 0.05$

** $p < 0.01$

Table 11

Tertile-Split Mean Comparisons (N=54)

Variables	Authoritative (n=17)		Authoritarian (n=10)		Permissive (n=9)		Neglectful (n=18)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Adherence								
Frequency	3.92	.38	3.58	.39	3.61	.24	3.52	.42
Responsibility	2.40	.70	2.04	.66	2.21	.55	2.11	.64
Average HgbA1c	8.06	1.04	8.49	.86	8.95	1.49	8.46	.83
Quality of Life								
Impact	46.41	11.47	55.10	20.50	47.11	6.79	51.67	9.99
Worry	19.29	8.00	26.80	14.38	19.89	9.71	21.78	8.43
Satisfaction	65.00	19.37	60.70	12.34	60.44	8.89	62.50	9.43

Table 12

Tertile-Split t-tests (N=54)

Variables	Authoritative/Authoritarian		Authoritative/Permissive		Authoritative/Neglectful	
	t	*p*	t	*p*	t	*p*
Adherence						
Frequency	2.212	.036*	2.167	.020*	2.817	.008**
Responsibility	1.323	.198	.694	.494	1.233	.226
Average HgbA1c	-1.117	.275	-1.780	.088	-1.272	.212
Quality of Life						
Impact	-1.421	.168	-.167	.869	-1.447	.157
Worry	-1.753	.154	-.168	.868	-.893	.378
Satisfaction	.628	.535	.665	.513	.490	.635

* $p < 0.05$

** $p < 0.01$

Table 13

Descriptions of K-Means Cluster Groups

Variables	n	Mean	SD
Adherence Frequencies			
Authoritative	37	3.81	.357
Authoritarian	16	3.52	.531
Permissive	45	3.54	.434
Neglectful	4	3.25	.319
Metabolic Control -HgbA1c			
Authoritative	37	8.39	1.17
Authoritarian	16	8.49	1.16
Permissive	45	8.36	1.09
Neglectful	4	8.47	.41
Quality of Life - Impact			
Authoritative	37	46.05	11.33
Authoritarian	16	56.94	17.83
Permissive	45	49.51	8.84
Neglectful	4	54.25	13.94
Quality of Life – Worry			
Authoritative	37	18.14	7.20
Authoritarian	16	25.75	11.44
Permissive	45	21.60	8.29
Neglectful	4	19.00	6.88
Quality of Life - Satisfaction			
Authoritative	37	67.35	15.01
Authoritarian	16	60.50	11.41
Permissive	45	64.16	9.23
Neglectful	4	55.75	10.15

Table 14

K-Means Clusters Between Parenting Style Groups t-tests

Variables	Authoritative/Authoritarian		Authoritative/Permissive		Authoritative/Neglectful	
	t	*p*	t	*p*	t	*p*
Adherence						
Frequency	2.33	.024*	3.048	.003**	3.005	.005**
Average HgbA1c	-.27	.790	.126	.900	-.133	.895
Quality of Life						
Impact	-2.25	.035*	-1.552	.125	-1.348	.185
Worry	-2.46	.023*	-1.998	.049*	-.229	.820
Satisfaction	1.63	.109	1.131	.263	1.500	.142

* $p < 0.05$

** $p < 0.01$

Table 15

K-Means Clusters Between Parenting Style Groups ANOVA

Variables	Between groups	F	*p*
Adherence			
Frequency		4.400	.006**
Average HgbA1c		.055	.983
Quality of Life			
Impact		3.443	.020*
Worry		3.250	.025*
Satisfaction		2.007	.118

* $p < 0.05$

** $p < 0.01$

Table 16

K-Means Clusters Between Parenting Style Groups Least Significant Difference (LSD)

Variables	Authoritative / Authoritarian		Authoritative / Permissive		Authoritative / Neglectful	
	Mean Difference	*p*	Mean Difference	*p*	Mean Difference	*p*
Adherence						
Frequency	.29003	.024*	-.56151	.013*	.56151	.013*
Average HgbA1c	-.0931	.781	.0315	.899	-.0791	.893
Quality of Life						
Impact	-10.88	.002**	-3.457	.186	-8.196	.186
Worry	-7.615	.003**	-3.465	.068	-.865	.846
Satisfaction	6.851	.059	3.196	.233	11.601	.069

* $p < 0.05$

** $p < 0.01$

Metabolic Control

Research questions 7, 8, and 9 ask "Is there a difference in metabolic control between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive or neglectful parenting styles?" *T*-test analyses were also used to test the following null hypotheses for these three questions:

HO 7 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HO 8 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HO 9 There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

In these analyses, whether using the mean-split technique, the tertile-split technique or the K-means cluster technique (Tables 10, 12, & 14) the results were insufficient to reject the null hypotheses HO 7, HO 8, and HO 9. Similarly, no significance results were found using the ANOVA with the K-means cluster technique (Table 15). Research questions 7, 8, and 9 were answered negatively; "There were no differences in metabolic control means (HgbA1c values) between adolescents who perceive their parents to have authoritative parenting styles and

adolescents who perceive their parents to have authoritarian, ... permissive .... or neglectful parenting styles." Table 17 reflects the average HgbA1c's mean, standard deviation, and range from the sample population.

Table 17

HgbA1c Means, Standard Deviations, and Range (N=102)

Variable	Mean	SD	Range
Average HgbA1c	8.40	1.10	6.3 - 12

Quality of Life

Research questions 10, 11, and 12 ask "Is there a difference in perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive or neglectful parenting styles?" The analysis for quality of life was based on the three subscales for quality of life: impact, worry, and satisfaction. The following null hypotheses were tested using the t-test analysis with the mean-split and the tertile-split technique (Tables 10 & 12).

HO 10 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian parenting styles.

HO 11 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have permissive parenting styles.

HO 12 There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles.

According to Levene's test for equal variances, all variables met the assumptions for equal variances except for the quality of life-impact scores in the analyses between the authoritative parenting style and authoritarian parenting style and the quality of life-satisfaction scores in the analyses between the authoritative parenting style and the neglectful parenting style. The latter was not found significant and was not further analyzed. With respect to the quality of life–impact scores, the non-parametric Mann-Whitney test was used to determine the significance of this variable with respect to the difference in the authoritative and the authoritarian parenting styles. Based on the Mann-Whitney test the quality of life-impact scores were not found to be significant between authoritative and authoritarian parenting styles ($z = -1.841$, $p = .066$). All analyses, therefore, (using the mean-split or tertile-split techniques) between quality of life (impact, worry, or satisfaction) for adolescents who perceived their parents to have authoritative parenting styles and adolescents who perceived their parents to have authoritarian, permissive or neglectful parenting styles failed to reject the null hypotheses pursuant to research questions 10, 11, and 12.

The K-means cluster analyses, for these research questions, however, provided different results. *T*-tests were run for the K-means cluster analyses as well. Levene's test showed most variables met the assumptions for equal variances except quality of life-impact and quality of life-worry in the analyses between the authoritative parenting style and authoritarian parenting style and the quality of life-satisfaction scores in the analyses between the authoritative parenting style and the permissive parenting style. For each of these variables the non-parametric Mann-Whitney test was used to determine the significance of these variables with respect to the different parenting group analyses. Based on the Mann-Whitney test the quality of life-impact scores and quality of life-worry scores were found to be significant between authoritative and authoritarian parenting styles (impact, $z = -2.318$, $p = .020$; worry, $z = -2.545$, $p = .011$). Additionally, the Mann-Whitney test also showed quality of life-satisfaction scores to be significant between authoritative and permissive parenting styles ($z = -2.168$, $p = .030$) whereas the *t*-test did not show significance (Table 18).

Table 18

Non-Parametric Tests – Mann-Whitney

Variable	Parenting Style Cluster	Parenting Style Cluster	Mann-Whit. *Z*	Sig. *p*
Quality of Life				
Impact	Authoritative	Authoritarian	-2.318	.020*
Worry	Authoritative	Authoritarian	-2.545	.011*
Satisfaction	Authoritative	Permissive	-2.168	.030*

*$p < .05$

Additionally, an ANOVA was run to test for differences among the means, to complement the *t*-test analyses and further validate the results. In this analysis a significant difference was found between parenting groups for quality of life-impact, and qualify of life-worry (Table 15). The test for homogeneity of variance did show that the quality of life-impact score also violated the equal variance assumption. As the normality of the distribution was questionable, the Kruskal-Wallis non-parametric test was run. The results (Chi-Square = -8.402, df = 3, p = .038) suggest a significant difference with respect to center (medians) in terms of quality of life-impact and the means for the different parenting groups.

To help determine which groups demonstrate the differences a post hoc analysis was run using the Least Significant Difference (LSD) analysis (Table16). Related to quality of life-impact, there was a significant difference between the authoritative parenting style group and the authoritarian parenting style group. Additionally, there was a significant difference between the authoritative parenting style group and the authoritarian parenting style group using the quality of life-worry scale as well. Based on these results it was concluded that null hypothesis HO 10 be rejected and research question 10 be answered affirmatively: "Adolescents who perceive their parents to have authoritative parenting styles have better perceived quality of life than adolescents who perceive their parents to have authoritarian parenting styles."

Because equal variances and normal distribution assumptions were not always met, additional non-parametric post hoc procedures were completed. Since the quality of life-impact score violated the equal variance assumption, the Mann–Whitney test was used to compare each paring of parental groups separately, related to the quality of life–impact scores. In this analysis, quality of

life–impact was found to be significant between authoritative and authoritarian parenting style groups (Z = -2.318, p = .020). In addition, a significant difference was found between the authoritative and permissive parenting style groups (Z = -2.117, p = .034). Furthermore, because the distribution graphs for quality of life-worry were skewed to the right, even though the variances were determined satisfactorily equal, a Kruskal-Wallis test was performed. The results showed a significant difference between the quality of life-worry and the different parenting styles (Chi-Square = 9.347, df = 3, p = .025). In light of these results one would also reject null hypothesis HO 11 and answer research question 11 affirmatively; "Adolescents who perceive their parents to have authoritative parenting styles have better perceived quality of life than adolescents who perceive their parents to have permissive parenting styles."

There was not enough evidence demonstrating a significant difference in the perceived quality of life between adolescents who perceived their parents to have authoritative parenting styles and adolescents who perceived their parents to have neglectful parenting styles. Based on this analysis, research question 12 is answered negatively and null hypothesis HO 12 is accepted: "There is no difference in the perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have neglectful parenting styles."

Table 19 summarizes the significant t-tests, ANOVA's, and the non–parametric tests used in the above analyses. The identified results are represented by the *p* values.

Table 19

K-Mean Clusters Analysis and Summary of Significant t-tests, ANOVA's and Non-parametric tests represented by p values

Variables			A/A			A/P			A/N		
	ANOVA	NP	*t*	LSD	NP	*t*	LSD	NP	*t*	LSD	NP
Adherence											
Frequency	.006**	-	.024*	.024*	-	.003**	.013*	-	.005**	.013*	
Average HgbA1c	-	-	-	-	-	-	-	-	-	-	
Quality of Life											
Impact	.020*	.038*a	.035*	.002**	.020*b	-	-	.034*b	-	-	
Worry	.025*	.025*a	.023*	.003**	.011*b	.049*	-	-	-	-	
Satisfaction	-	-	-	-	-	-	-	.030*b	-		-

Authoritative/Authoritarian = A/A
Authoritative/Permissive = A/P
Authoritative/Neglectful = A/N
Non-parametric = NP
Kruskal-Wallis = a
Mann-Whitney = b

* $p < 0.05$

** $p < 0.01$

A multiple regression was also run to determine if the independent variable of parenting style would predict metabolic control, adherence, or quality of life. The demographic variables of gender, age, grade, ethnicity, family structure, and mother's and father's educational level were also entered into the equation. As in the regression analysis with parental support, the only variable to demonstrate a level of significance was adherence (Multiple R = .345; R^2 = .119; $p < .01$). In this case, parenting style as defined by the K-means cluster analysis can predict adherence, but it only explains approximately 12% of the variability in adherence.

CHAPTER 5

SUMMARY AND DISCUSSION

This final chapter will restate the research problem and review the major methods used in the study. The major sections of this chapter summarize the results and discuss their implications.

This study explored specific dimensions of parental support (perceived support and parenting styles) that research suggested could enable the adolescent, 12 to 18 years of age, to effectively manage his or her insulin dependent diabetic health care and promote a sense of quality of life. This cross-sectional quantitative causal comparative study was carried out in a natural setting. The unit of analysis was the adolescent between 12 and 18 years of age. Adolescents were targeted if they were in the designated age range, had been diagnosed with insulin dependent diabetes for at least one year, met the criteria, and attended a large pediatric endocrinology clinic in West Michigan. Adolescents were approached as they came to the clinic for their quarterly visit to the pediatric endocrinologist. Most adolescents took the questionnaires home for completion and returned them in a pre-addressed stamped envelope.

The focus of the study was the parent-adolescent relationship and how dimensions of parental support through perceived support and parenting style would facilitate the adolescents' management of their diabetes. The family ecological model with its emphasis on family systems, interactions, and environments grounded this research.

This study found that perceived parental support and authoritative parenting styles do impact the adolescents' ability to manage their diabetic health care as well as favorably influence their quality of life. Table 20 summarizes the results of the null hypotheses outcomes. In the following paragraphs, the results will be summarized as they relate to the independent variables, perceived parental support and parenting styles.

Perceived Parental Support

The research objective for the first three hypotheses was to investigate the relationship between perceived levels of parental support and adolescents' adherence measures, metabolic control, and perceived quality of life. This discussion follows.

Adherence. The analyses showed a significant relationship between parental support and adolescents' adherence with their diabetic health management. This supports the findings of other researchers that there is a relationship between supportive behaviors of parents and adherence measures of adolescents with diabetes (Burroughs et al. 1997). Adolescents' diabetic management is better when parents are involved, responsive and caring (Anderson et al. 1997; Burroughs et al. 1993; Hanna & Guthrie, 2001; Hanson et al. 1987a; Hanson et al. 1987c; Kyngas & Rissanen, 2001). In this study, approximately 17% of the variation in adherence was explained by perceived parental support.

Metabolic Control. There was no relationship found between perceived parental support and metabolic control. On one hand, this was an expected result. Other researchers also failed to find a relationship between positive and encouraging parental support and metabolic control (Hanson, DeGuire, et al.

Table 20

Summary of Null Hypotheses Outcomes

Null Hypothesis	Variables Independent	Dependent	Outcomes Accepted / Rejected
HO 1	Parental Support	Adherence	R
HO 2	Parental Support	Metabolic Control	A
HO 3	Parental Support	Quality of Life	R
HO 4	Parenting Style Authoritative / Authoritarian	Adherence	R
HO 5	Parenting Style Authoritative / Permissive	Adherence	R
HO 6	Parenting Style Authoritative / Neglectful	Adherence	R
HO 7	Parenting Style Authoritative / Authoritarian	Metabolic Control	A
HO 8	Parenting Style Authoritative / Permissive	Metabolic Control	A
HO 9	Parenting Style Authoritative / Neglectful	Metabolic Control	A
HO 10	Parenting Style Authoritative / Authoritarian	Quality of Life	R
HO 11	Parenting Style Authoritative / Permissive	Quality of Life	R
HO 12	Parenting Style Authoritative / Neglectful	Quality of Life	A

1992; Schafer et al. 1983). Some researchers, however, have demonstrated a direct effect between adherence and metabolic control (Hanson et al. 1987a). As this study showed a significant relationship between parental support and adherence, one might expect to see a relationship between parental support and metabolic control. However, in this study metabolic control and adherence were not related. Most likely, there are other factors involved that affect metabolic control that were not accounted for in this study. For example, Hanson et al. (1987c), while looking to see if parental support would mediate a link between stress and metabolic control, found "stress" to have a direct link to metabolic control. In 1989, Hanson et al. found associations between family support and metabolic control to be mediated by the duration of diabetes. Neither stress nor length of diabetes were directly measured in this study.

Additionally, physiological factors such as hormonal changes related to puberty may be another factor. Hormonal changes have been associated with decreased sensitivity to insulin, requiring more insulin in even healthy adolescents. The need for more insulin is compounded for the adolescent with diabetes contributing to the difficulty in achieving good metabolic control (Amiel et al. 1986). It is still interesting to note, as stated earlier, that a negative trend in the relationship between parental support and metabolic control was found. As parental support scores increased, there was a non-significant trend for the average HgbA1c to decrease. It is possible that a statistically significant relationship might be seen with a larger sample.

Quality of Life. Perceived parental support was correlated with quality of life as measured through satisfaction. This was consistent with what has been found in the literature. Grey et al. (1998) found that adolescents who were more

satisfied with their quality of life reported having families that were perceived as more supportive (warm and caring). Adolescents who were more satisfied with their quality of life, reported fewer symptoms of depression and found coping with diabetes easier and less upsetting.

In this present study, adolescents felt pretty good about their diabetes overall. They expressed low to moderate impact and worry about their diabetes and moderate satisfaction related to their quality of life.

On the other hand, perceived parental support, although correlated with quality of life as measured through satisfaction, did not correlate with quality of life as measured though impact or worry. Grey et al. (1998) also reported family functioning, as measured by the Family Adaptability and Cohesion Scale, did not significantly correlate with quality of life. This same study found some adolescents reporting diabetes as having a large impact on their life. Adolescents who typically reported more impact were more likely to see the management of diabetes as harder and more upsetting. Also, adolescents who worried more had more symptoms of depression and found coping with diabetes more difficult. It would seem that adolescents who see their diabetic management as harder or more difficult to cope with might tend to respond differently to behaviors expressing caring or parental support measures related to diabetic care. Other factors such as the stress of diabetes may be intervening.

Parenting Style

The second research objective was to investigate differences in adherence measures, metabolic control and perceived quality of life between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive, or neglectful

parenting styles. Three different methods were used to categorize adolescents' scores reflecting their perceptions of their parents' responsiveness and demandingness in terms of parenting style. The K-means cluster analyses technique tended to provide more clarity in distinguishing between the authoritative, authoritarian, permissive and neglectful groups compared to the median-split or tertile-split techniques and is a preferred method for some researchers (N. Darling, personal communication, March 16, 2006). It is important to note that this categorization was purely heuristic--for research purposes only--and was not meant to diagnose any certain parenting style group. The parenting style typology was meant to describe normal variations in parenting and was not intended to identify deviant parenting practices such as seen in neglectful homes (Darling, n.d.). The discussion follows.

Adherence. Adolescents who perceived their parents to have authoritative parenting styles had better adherence to their prescribed treatment plan than adolescents who perceived their parents to have authoritarian, permissive or neglectful parenting styles. This was an anticipated finding based on the social support literature on parenting style. Family cohesion is often associated with better adherence whereas family conflict is associated with poorer adherence (Hauser et al. 1990; Miller-Johnson et al. 1994). It was also a new finding. Although, many researchers investigating parental support studied certain characteristics of parenting styles such as warmth and control, no one has studied the parenting style typology exclusively with adolescents with diabetes.

Characteristics of the authoritative parent can influence adherence in a number of ways. Authoritative parenting can foster a positive family milieu resulting in reduced family conflict and/or an increase in family cohesion. These

children are usually happier, exhibit higher self-esteem, and perform better socially and academically. Social competence has also been associated with better adherence (Hanson et al. 1987c).

Metabolic Control. There is no difference in metabolic control (HgbA1c) between adolescents who perceive their parents to have authoritative parenting styles and adolescents who perceive their parents to have authoritarian, permissive or neglectful parenting styles. This is consistent with the result that there was no relationship between parental support and metabolic control and was an expected finding. Metabolic control seems to be associated with other factors such as stress as already identified above. The study by Hanson et al. (1987c) showed that stress was directly associated with metabolic control and that "the interaction between parental support and stress did not buffer the negative effects of stress" (p. 532).

Quality of Life. Based on one or more of three measures of quality of life (impact, worry, or satisfaction) adolescents who perceived their parents to have authoritative parenting styles had better perceived quality of life than did adolescents who perceived their parents to have authoritarian or permissive parenting styles. This statement reflects two of the alternative hypotheses that were supported. These findings were in slight contrast to analyses between parental support and quality of life which only found satisfaction to be significantly correlated with parental support. This may be explained by the fact that the tools are measuring different dimensions of the parent-child experience. The parental support questionnaire focused on enacted support related to diabetic management with an element of caring. The parenting style questionnaire focused on the "emotional climate in which particular parent-child

interactions occur" (Darling & Toyokawa, 1997, p. 2). It would be expected that perceptions of quality of life would be higher in an environment characterized by warmth, involvement, high expectations and gentle guidance such as seen with an authoritative parenting style.

Limitations

One of the limitations of this study was sample size. Although it was large enough for some analyses, it became too small when the sample was broken down into sub-groups, as when analyzing the parenting style groups. Sample size affects the power of the study. For a power of .80 and a moderate effect size, a sample size of approximately 120 subjects would have been desirable. Even more subjects may have been helpful depending on how they fell into the different parenting style groups. For example, there were only four subjects in the neglectful parenting style group (K-means cluster analysis). The small sample size of this group precludes the reliability and validity of any analyses done with that group. It also explains why no significance was found in all but one of the analyses involving that group.

Additionally, the sample may not be representative of the entire population of adolescents with Type 1 diabetes, thus affecting the generalizability of this study. In this particular study there was very little ethnic diversity. It would be helpful to obtain national, state, or county-wide registries to determine actual ethnic demographics. Ideally sample populations could be drawn from more than one geographic location to assure better diversity within the groups.

Implications for Practice

As responsibility for diabetic health care management transitions from parent to child from late childhood through adolescence, parents need to be made

aware of the crucial role they play in fostering good diabetic health care management. Positive parental support was shown to be a significant predictor of adherence. It has also been associated with better quality of life. This has implications for clinical practice. Research has shown that adolescents need acceptance, genuine interest, motivation, encouragement, and positive feedback (Anderson et al. 1997; Kyngas, & Rissanen, 2001; LaGreca et al. 1995). Health care providers are in a position to share the significance of parental support with parents of adolescents with diabetes and to help parents distinguish helpful involvement from more intrusive involvement. According to Grey et al. (1998), the challenge is to find "parental involvement that is individualized for the adolescent, without risking poorer control from over-involvement or under-involvement" (p. 913). The emphasis should be on the adolescent. Practitioners must recognize that adolescents are worried about their future health, and may need help in attempting to balance these concerns with other developmentally appropriate tasks of adolescence (Farro, 1999). Practitioners and parents need to understand the diabetic experience of the adolescent to help determine the appropriate support, family environment, and parenting activities that would foster good diabetic health management.

Implications for Future Research

Authoritative parenting styles can have positive outcomes for adolescents with Type 1 diabetes in terms of adherence and quality of life. To better understand the influence of the authoritative parent on an adolescent with diabetes and his or her diabetic health management, more research is needed to further explore the milieu, the relationships, and interactions between the parent and child/adolescent. Qualitative studies of adolescents with authoritative

parents may give better insight into the environment, interactions, day-to-day challenges and strategies related to management of Type 1diabetes that contribute to better outcomes. Additionally, as adolescents become more capable of self-management, the emphasis should be on interdependence. Parents need to remain involved. "Focusing on autonomy of the adolescent and facilitating interdependence between parent and adolescents is an important direction for research" (Anderson, 2001,p.649).

Conclusion

Successful management of Type1 diabetes in adolescents remains a challenge. Research has shown that adolescents experience better outcomes related to management when parents remain involved. The new theoretical focus for adolescents with diabetes is to move from "independence to interdependence" (Anderson, 2001). Parents who are perceived to be supportive and authoritative in their parenting style seem to promote a sense of interdependence as they encourage and promote adolescent autonomy. Autonomous individuals would seem to have less worries, more satisfaction, and better health management outcomes. More research needs to be done on how parents can nurture the development of more autonomous individuals in order to facilitate better health care outcomes for adolescents with Type 1 diabetes. Metabolic control may not be the only outcome variable to measure good diabetic health. Quality of life is important. Good parenting can foster this.

APPENDICES

APPENDIX A

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABERTES INFORMATION SHEET

Parental Support and Adolescent Health Management of Diabetes

Information sheet

ID # _____

What is your sex? ☐ Male ☐ Female

What is your ethnic group?
☐ Black ☐ White
☐ Hispanic ☐ Asian American
☐ American Indian ☐ Other

When were you born? _____/____/_____ Age _____
Month Day Year

What is your family structure?
☐ Two natural parents ☐ Single/divorced parent
☐ Stepfamily ☐ Other

How much education did your parents complete?

Father	Mother
☐ High school or less	☐ High school or less
☐ College completion or more	☐ College completion or more

How old were you when you were first told you had diabetes? _____

In what grade are you currently enrolled? _____

Approximately how many days of school did you miss in the last year because of your diabetes? _____

Please do not place your name on any subsequent sheet of paper/questionnaire. In the following questionnaires please **answer each question** by circling or checking the answer that best reflects your choice. Thank you for being honest and thorough. There are no wrong answers.

APPENDIX B

HGBA1C FORM

HgbA1c Form

Initials _____ ID # _____

HgbA1c – Please record the last four values post the honeymoon phase.

1. _____
2. _____
3. _____
4. _____

APPENDIX C

PARENTAL SUPPORT QUESTIONNAIRE

PARENTAL SUPPORT QUESTIONNAIRE

Teens' Perceptions of Parents' Help with Diabetes Care: Think about the things that your parents do to help you be responsible for your diabetes care in the past 3 months. First, circle the number or check the box that describes how often your parents did the following things. Then for the things they have done, circle the number or check the box that describes how helpful these things were. Give insulin means pump or injection. There are no right or wrong answers.

In the past 3 months:	**How often have your parent(s):**						**How helpful was it when your parent(s):**				
	None of of the time				**All the time**		**Not at All Helpful**				**Very Helpful**
1. Asked you "what do you think needs to done about your insulin."	1	2	3	4	5		1	2	3	4	5
2. Showed you how to figure insulin dose.	1	2	3	4	5		1	2	3	4	5
3. Suggested that you give insulin before telling you to do it.	1	2	3	4	5		1	2	3	4	5
4. Answered your questions about figuring insulin dose.	1	2	3	4	5		1	2	3	4	5

END OF PARENTAL SUPPORT QUESTIONNAIRE

APPENDIX D

PARENTING STYLE INVENTORY – II

PARENTING STYLE INVENTORY – II

Please indicate how much you agree or disagree with the following statements: (Please answer all questions where applicable for the parent(s) you live with)

5= Strongly Agree
4= Agree
3= I'm in Between
2= Disagree
1= Strongly disagree

Mother

	Strongly Disagree				Strongly Agree
1. My mother really expects me to follow family rules.	1	2	3	4	5
2. My mother doesn't really like me to tell her my troubles.	1	2	3	4	5
3. My mother tells me that her ideas are correct and that I shouldn't question them.	1	2	3	4	5
4. My mother really lets me get away with things	1	2	3	4	5
5. My mother hardly ever praises me for doing well.	1	2	3	4	5
6. My mother respects my privacy.	1	2	3	4	5
7. If I don't behave myself, my mother will punish me.	1	2	3	4	5
8. I can count on my mother to help me out if I have a problem.	1	2	3	4	5
9. My mother gives me a lot of freedom.	1	2	3	4	5
10. My mother points out ways I could do better	1	2	3	4	5
11. My mother spends time just talking to me	1	2	3	4	5
12. My mother makes most of the decisions about what I can do	1	2	3	4	5
13. When I do something wrong, my mother does not punish me.	1	2	3	4	5
14. My mother and I do things that are fun together	1	2	3	4	5
15. My mother believes I have a right to my own point of view.	1	2	3	4	5

Father

	Strongly Disagree				Strongly Agree
1. My father really expects me to follow family rules.	1	2	3	4	5
2. My father doesn't really like me to tell him my troubles.	1	2	3	4	5
3. My father tells me that his ideas are correct and that I shouldn't question them.	1	2	3	4	5
4. My father really lets me get away with things.	1	2	3	4	5
5. My father hardly ever praises me for doing well.	1	2	3	4	5
6. My father respects my privacy.	1	2	3	4	5
7. If I don't behave myself, my father will punish me.	1	2	3	4	5
8. I can count on my father to help me out if I have a problem.	1	2	3	4	5
9. My father gives me a lot of freedom.	1	2	3	4	5
10. My father points out ways I could do better.	1	2	3	4	5
11. My father spends time just talking to me.	1	2	3	4	5
12. My father makes most of the decisions about what I can do.	1	2	3	4	5
13. When I do something wrong, my father does not punish me.	1	2	3	4	5
14. My father and I do things that are fun together.	1	2	3	4	5
15. My father believes I have a right to my own point of view.	1	2	3	4	5

End of Parenting Style Inventory

APPENDIX E

DIABETES BEHAVIOR RATING SCALE

B. MODIFICATIONS OF DIABETES CARE PLAN

There are some adjustments that need to be made in diabetes care in certain situations. These may or may not be done on a daily basis. We are interested in knowing how often these behaviors are practiced when called for.

How Often Done as Prescribed

5 = Always
4 = Usually
3 = About half the time
2 = Seldom
1 = Never

Degree of Child's Responsibility

A = Child totally responsible
B = Child mostly responsible
C = Shared Responsibility
D = Parent mostly responsible
E = Parent totally responsible

When it is appropriate to do, how often:

16.	are meals and snacks changed because of amount of exercise?	1 2 3 4 5	A B C D E
17.	is insulin dose changed when physical activity changes in order to prevent low blood sugar?	1 2 3 4 5	A B C D E
18.	is insulin dose changed when meal times are changed (e.g., late dinner or holiday meal)?	1 2 3 4 5	A B C D E
19.	are exercise levels changed because of blood sugar levels?	1 2 3 4 5	A B C D E

C. INTERVENTION BEHAVIORS

There are also actions that are taken only when your child has symptoms of "low" or "high" blood sugar. Many of these actions are listed below. We are interested in knowing how often these behaviors are practiced when your child has symptoms.

How often:

20.	are blood sugar levels tested when blood sugar levels might be too "low" or "high"?	1 2 3 4 5	A B C D E
21.	is help obtained for diabetes in school, home, or social settings?	1 2 3 4 5	A B C D E
22.	is insulin dose changed based on results of blood sugar levels?	1 2 3 4 5	A B C D E
23.	is "fast sugar" eaten when blood sugar level is "low"?	1 2 3 4 5	A B C D E
24	is "regular food" eaten after needing to take "fast-sugar"?	1 2 3 4 5	A B C D E

There are many behaviors required on the part of parents and their children to manage diabetes on a day-to-day basis. Some of them are described below. We would like to know how often these behaviors are practiced. We would also like to know how much responsibility your child takes in his or her own diabetes care.

A. DAILY PREVENTION BEHAVIORS

The following behaviors are done on a daily basis. They are intended to prevent symptoms of hypoglycemia and hyperglycemia and to help keep diabetes under control.

How Often Done as Prescribed

5 = Always
4 = Usually
3 = About half the time
2 = Seldom
1 = Never

Degree of Child's Responsibility

A = Child totally responsible
B = Child mostly responsible
C = Shared Responsibility
D = Parent mostly responsible
E = Parent totally responsible

How often:

1.	are meals planned according to the food exchange system?	1 2 3 4 5	A B C D E
2.	are foods weighed and measured?	1 2 3 4 5	A B C D E
3.	are food labels used for planning meals?	1 2 3 4 5	A B C D E
4.	are meals eaten at the same time each day?	1 2 3 4 5	A B C D E
5.	are snacks eaten at the same time each day?	1 2 3 4 5	A B C D E
6.	is insulin given daily in the dose prescribed?	1 2 3 4 5	A B C D E
7.	is insulin dose written in a daily log?	1 2 3 4 5	A B C D E
8.	is insulin drawn up correctly?	1 2 3 4 5	A B C D E
9.	is insulin injection given correctly?	1 2 3 4 5	A B C D E
10.	are insulin injections given in different parts of the body?	1 2 3 4 5	A B C D E
11.	are insulin and supplies cared for in the right way?	1 2 3 4 5	A B C D E
12.	are blood sugar levels tested when it should be (according to doctor's instructions)?	1 2 3 4 5	A B C D E
13.	are results of blood sugar tests written in a daily log?	1 2 3 4 5	A B C D E
14.	is a quick-acting carbohydrate ("fast sugar") carried?	1 2 3 4 5	A B C D E
15.	is diabetes identification worn?	1 2 3 4 5	A B C D E

	How Often Done as Prescribed	Degree of Child's Responsibility
	5 = Always 4 = Usually 3 = About half the time 2 = Seldom 1 = Never	A = Child totally responsible B = Child mostly responsible C = Shared Responsibility D = Parent mostly responsible E = Parent totally responsible

D. ILLNESS

Diabetes care sometimes changes when your child has the flu or another illness.

When your child is ill, how often:

25.	are extra liquids given?	1 2 3 4 5	A B C D E
26.	is the doctor/nurse called for changes in insulin dose when the child is unable to eat?	1 2 3 4 5	A B C D E
27.	is blood sugar level tested every 3 to 4 hours?	1 2 3 4 5	A B C D E
28.	is urine tested for ketones?	1 2 3 4 5	A B C D E

E. SUPPLIES

Diabetes care requires the use of medical supplies. We are interested in knowing how these supplies are maintained.

How often:

29.	is there enough insulin for shots?	1 2 3 4 5	A B C D E
30.	are there enough insulin syringes?	1 2 3 4 5	A B C D E
31.	is there enough supplies for testing blood sugar levels?	1 2 3 4 5	A B C D E
32.	is there enough supplies for checking urine ketone levels?	1 2 3 4 5	A B C D E

F. OTHER DIABETES CARE PRACTICES

There are other important diabetes care behaviors that do not occur very often. Please answer the following questions about these behaviors:

33.	How often are meals eaten away from the home (e.g., at restaurants, parties) considered in making the daily meal plan?	1 2 3 4 5	A B C D E
34.	When necessary, how often are people who make food told about the child's diabetes?	1 2 3 4 5	A B C D E
35.	When urine ketones are tested, how often are the results written in log book?	1 2 3 4 5	A B C D E

F. OTHER DIABETES CARE PRACTICES
(Continued)

	How Often Done as Prescribed	Degree of Child's Responsibility
	5 = Always 4 = Usually 3 = About half the time 2 = Seldom 1 = Never	A = Child totally responsible B = Child mostly responsible C = Shared Responsibility D = Parent mostly responsible E = Parent totally responsible

How often:

36.	are key people in your child's life told how to treat "low" blood sugar?	1 2 3 4 5	A B C D E
37.	are health care providers called for changes in insulin dose because of frequent "high" or "low" blood sugar levels?	1 2 3 4 5	A B C D E
38.	is the doctor notified when your child has severe diabetic symptoms (e.g., drinking a lot, needing fast sugar a lot)?	1 2 3 4 5	A B C D E
39.	are all health care providers (physicians, school nurses, dentists, and so on) told that your child has diabetes?	1 2 3 4 5	A B C D E

APPENDIX F

DIABETES QUALITY OF LIFE –YOUTH - SCALE

DIABETES QUALITY OF LIFE –YOUTH

Please indicate how you agree or disagree with the following statements:

5= Always
4= Often
3= About half the time
2= Seldom
1= Never

Impact of Diabetes	Never				Always
1. How often do you feel pain associated with the treatment for your diabetes?	1	2	3	4	5
2. How often are you embarrassed by having to deal with your diabetes in public?	1	2	3	4	5
3. How often do you feel physically ill?	1	2	3	4	5
4. How often does your diabetes interfere with your family life?	1	2	3	4	5
5. How often do you have a bad night's sleep?	1	2	3	4	5
6. How often do you find your diabetes limiting your social relationships and friendship?	1	2	3	4	5
7. How often do you feel good about yourself?	1	2	3	4	5
8. How often do you feel restricted by your diet?	1	2	3	4	5
9. How often does your diabetes keep you from driving a car or using a machine (for example, a typewriter)?	1	2	3	4	5
10. How often does your diabetes interfere with your exercising?	1	2	3	4	5
11. How often do you miss work, school, or household duties because of your diabetes?	1	2	3	4	5
12. How often do you find yourself explaining what it means to have diabetes?	1	2	3	4	5
13. How often do you find that you diabetes interrupts your leisure-time activities?	1	2	3	4	5
14. How often do you get teased because you have diabetes?	1	2	3	4	5
15. How often do you feel that because of your diabetes you go to the bathroom more than others?	1	2	3	4	5
16. How often do you find you eat something you shouldn't rather than tell someone that you have diabetes?	1	2	3	4	5
17. How often do you hide from others the fact that you are having an insulin reaction?	1	2	3	4	5
18. How often do you find that your diabetes prevents you from participating in school activities (for example, being active in a school play, being on a sports team, being in a school band, etc.)?	1	2	3	4	5
19. How often do you find that your diabetes prevents you from going out to eat with your friends?	1	2	3	4	5
20. How often do you feel that your diabetes will limit what job you will have in the future?	1	2	3	4	5
21. How often do you find that your parents are too protective of you?	1	2	3	4	5
22. How often do you feel that your parents worry too much about your diabetes?	1	2	3	4	5
23. How often do you find that your parent's act like diabetes is their disease and not yours?	1	2	3	4	5

Worries About Diabetes

	Never				Always
1. How often do you worry about whether you will get married?	1	2	3	4	5
2. How often do you worry about whether you will have children?	1	2	3	4	5
3. How often do you worry about whether you will not get a job you want?	1	2	3	4	5
4. How often do you worry about whether you will pass out?	1	2	3	4	5
5. How often do you worry about whether you will be able to complete your education?	1	2	3	4	5
6. How often do you worry that your body looks different because you have diabetes?	1	2	3	4	5
7. How often do you worry that you will get complications from your diabetes?	1	2	3	4	5
8. How often do you worry about whether someone will not go out with you because you have diabetes?	1	2	3	4	5
9. How often do you worry that your teachers treat you differently because of your diabetes?	1	2	3	4	5
10. How often do you worry that your diabetes will disrupt something you are currently doing in school (for example, act in a play, continue on a sports team, be in a the school band, etc.)?	1	2	3	4	5
11. How often do you worry that because of your diabetes you are behind in terms of dating, going to parties, and keeping up with your friends?	1	2	3	4	5

5= Very satisfied
4= Somewhat satisfied
3= Neither
2= Somewhat unsatisfied
1= Very unsatisfied

Satisfaction With Life

	Very Unsatisfied				- Very Satisfied
1. How satisfied are you with the amount of time it takes to manage your diabetes?	1	2	3	4	5
2. How satisfied are you with the amount of time you spend getting checkups?	1	2	3	4	5
3. How satisfied are you with the time it takes to determine your sugar level?	1	2	3	4	5
4. How satisfied are you with your current treatment?	1	2	3	4	5
5. How satisfied are you with the flexibility you have in your diet?	1	2	3	4	5
6. How satisfied are you with the burden your diabetes is placing on your family?	1	2	3	4	5
7. How satisfied are you with your knowledge about your diabetes?	1	2	3	4	5
Speaking Generally:					
8. How satisfied are you with your sleep?	1	2	3	4	5
9. How satisfied are you with your social relationships?	1	2	3	4	5
10. How satisfied are you with your work, school, and household activities?	1	2	3	4	5
11. How satisfied are you with you're the appearance of your body?	1	2	3	4	5

(Satisfaction With Life)	Very Unsatisfied				Very Satisfied
12. How satisfied are you with you're the time you spend exercising?	1	2	3	4	5
13. How satisfied are you with your leisure time?	1	2	3	4	5
14. How satisfied are you with life in general?	1	2	3	4	5
15. How satisfied are you with your performance in school?	1	2	3	4	5
16. How satisfied are you with how your classmates treat you?	1	2	3	4	5
17. How satisfied are you with your attendance in school?	1	2	3	4	5

Compared with others your age, would you say your health is?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

END OF DQOLY

APPENDIX G

CONSENT FORMS

Research Informed Consent and HIPAA Authorization/Consent for Release of Health Information for Research Purposes

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

Principal Investigator: Dr. Robert Boger, Ph.D. Michigan State University
Secondary Investigator: Susan M. Mlynarczyk, RN. MSN. (Spectrum-health), PhDc, MSU

"You" refers to you or your child

INTRODUCTION:

You are being asked to participate in a research study. In order to decide whether or not you should agree to be part of this research study, you should receive enough information about its risks and benefits to make a judgment. This process is called informed consent.

This consent form gives detailed information about the research study, which will be discussed with you. If you wish to participate in this study, you will be asked to sign this form and you will be given a signed copy for your records.

NATURE AND PURPOSE OF THIS STUDY:

This study will explore the nature of support that enables the adolescent to most effectively manage their diabetic health care. The overall purpose of this research is to investigate varying degrees of parental support and how this may affect adolescents' diabetic health management, metabolic control and perceived quality of life for Grand Rapids area adolescents aged 12 to 18, diagnosed with insulin dependent diabetes.

Your adolescent is being asked to volunteer for this study because he/she is between the ages of 12 and 18 years, has had insulin dependent diabetes for at least one year, resides with at least one parent, speaks and reads English, has a diabetes treatment regimen that includes insulin injections or use of the insulin pump, glucose monitoring, meal planning and exercise; and does not have any diagnosed mental health issues.

This study will be conducted over the next three months with completion of data analysis in December of 2005. A total of around 150 adolescents at Spectrum Health are expected to participate in the study.

STUDY PROCEDURES:

Your participation is limited to the time it will take to fill out the demographic sheet and the four survey instruments. Once this is completed, your participation is complete. If you should run out of time to complete the questionnaires, you will be given a stamped addressed envelope in which to return your completed questionnaires at your earliest convenience.

It is expected that you will be able to complete the questionnaires while waiting for your different appointments with clinic staff. It should take approximately 20 to 25 minutes to complete all four questionnaires and the demographic sheet. When available a quiet room will be provided for you to fill out the questionnaires in private.

All adolescents meeting the criteria will be invited to participate in this study during the designated time frame until approximately 150 adolescents are selected.

RISKS, INCONVENIENCES AND DISCOMFORTS:
As this study mainly involves your responses to questionnaires, there is minimal risk involved. Any inconveniences incurred may be related to the time it takes to answer the questionnaires. For any questionnaires taken home, reminder cards/calls may follow to encourage completion and return of surveys.

POTENTIAL BENEFITS:
You may not directly benefit from your participation in this study. However, your participation may contribute to further understanding the social factors affecting the management of diabetes for adolescents. Participating in this study may result in no benefit to you.

COSTS/PAYMENT FOR STUDY PARTICIPATION:
There is no cost to you for participating in this study. The research investigators will cover any potential costs related to questionnaires being returned by mail.

Payment: Subjects completing the questionnaires will be mailed a $10 check for their participation. Additionally, each participant will be entered into a raffle drawing where $50 gift certificates will be given to four different individuals.

VOLUNTARY PARTICIPATION:
Participation in this research study is voluntary and you may refuse to enter the study or may discontinue participation in the study at any time without jeopardizing present and future medical care and treatment to which you are entitled. You will be informed of any changes in the nature of the study or in the procedures, which may be related to your willingness to continue participation in the study.

CONFIDENTIALITY:
The investigators, the clinic staff, delegated representatives from Spectrum Health, and/or the Spectrum Health Research and Human Rights Committee may inspect your medical records for informational purposes where appropriate and necessary via mail, electronic data, FAX or in person. Spectrum Health Research and Human Rights Committee will be acting as the Spectrum Health's Institutional Review Board and Spectrum Health Hospital's Privacy Board. Your privacy and confidentiality will be preserved to the full extent required by law.

Participants will be identified on a data sheet by name and study identification (ID) number only. All other forms (demographic sheet and questionnaires) will only have this identification number. The clinic research nurse obtaining your consent will be assigning you this ID number. The clinic research nurse will be the one maintaining the participant list. None of the clinic nurses (including the research nurse), office staff, doctors, other participants or parents will have access to the completed questionnaires. The principal/secondary investigator will collect the completed forms with only your ID number on them.

If questionnaires are taken home or missing responses are found on your questionnaires, the investigator will notify the clinic research nurse to contact you (possibly mailing you a new form) in order to receive all completed forms. At the completion of the data collection period, the secondary investigator and the clinic research nurse will determine the eligibility and winners of the raffled gift certificates. Your name will not be revealed in any reports or publications resulting from this study without your expressed consent.

HIPAA Authorization/Consent for Release of Health Information for Research Purposes

As part of the above research study, you are being asked to allow the release of your health information to the principal/secondary investigator and any of her representatives assisting with this research study. The Health Insurance Portability and Accountability Act (HIPAA) permits a hospital, or doctor's office (also known as a covered entities) to use or release Protected Health Information (PHI) for the purposes of treatment, payment or Health Care Operations. All other uses and releases of health information must be released by a HIPAA Authorization/consent. Authorization expresses legal permission from an individual to use or release PHI for research purposes. With limited exceptions, a covered entity may use or release PHI for research purposes only where permission has been given for such use and/or release.

1. What will you do with this information and why am I being asked to release this information?

This information will be collected and entered onto a database with the health information from others taking part in this study, and studied in order to determine if perceived parental support and different parenting styles affect adherence to diabetic health management, metabolic control and perceived quality of life. The HgbA1c from your medical record is needed to evaluate the metabolic control.

2. What are you asking me to release?

- We will collect information about you needed to complete this research study. This may include but may not be limited to your name and medical record number. For this study, it will also include your recent HbA1c values. Your doctor, the study investigator, or clinic research nurse may review your medical records for purposes of obtaining the pertinent medical history information and HgbA1c values.

3. Who will see this information?

Spectrum Health and the study personnel may use or release your PHI for purposes of the study to the following:

- The principal and secondary investigators and supporting staff (clinic staff, dissertation committee members, statistician).
- The Spectrum Health Research and Human Rights Committee.
- The Food and Drug Administration (FDA) and other governmental regulatory agencies.
- The Michigan State University Committee on Research Involving Human Subjects (UCRIHS)

It is expected that only the research nurse, clinic nurses and doctors will see your medical record. The secondary investigator may only see the medical record if it becomes necessary to record the HbA1c values or review the record to assure inclusion of subjects meeting the criteria of the study. The clinic research nurse will maintain the list of participants, with names and ID numbers. The research nurse, nursing staff, clinic doctors, parents or other participants will <u>not</u> have access to the completed surveys.

Your study records released outside of Spectrum Health will not personally identify you. Other than the principal/secondary investigator, those listed above may see parts of your medical records related to this study, but only identified by the ID number. The information collected and sent to the investigator is the property of the investigator, and you will not be able to get it back. In the event of any

publication regarding this study, your identity will not be released without your expressed consent.

We recognize that some of those who receive protected health information may not be required under federal regulations to keep your information confidential, so we cannot guarantee that your information will not be released or made available to another party once it leaves Spectrum Health. Therefore, we share this information only if necessary and we use all reasonable efforts to request that those who receive it take steps to protect your privacy.

Your access to your medical records will not be changed by the study. You have the right to see and copy your PHI related to the research study as long as this information is maintained by the study personnel or Spectrum Health.

4. Will the information you collect as part of this study be destroyed when it is no longer needed?

Your information, including participant list with ID number, will be kept at least until the study is completed and no longer needed, after which it will be carefully and properly disposed of.

5. Can I stop my information from being used?

Yes, you can withdraw this authorization at any time. Once you cancel your authorization, we will stop collecting your medical information. However, any information that was collected and sent before you revoked your authorization will continue to be used and be seen as described above. For example, study personnel may need to use or release information obtained before you withdrew your authorization in order to preserve the scientific integrity of the study.

While you may phone us and request to stop your participation in the research study, to discontinue the collection of your protected health information for study purposes, you must do so in writing.

If you decide to stop your participation in this study and stop the collection of your health information as well, you must send a notice to: *Dr. Boger or Sue Mlynarczyk, C/O Cook Research Department, 100 Michigan, NE, MC38, Grand Rapids, MI 49503.*

6. What if I do not authorize you to collect and release my health information?

If you decide not to authorize release of your health information as part of this study, your decision will in no way affect your medical care or cause you to lose any benefits to which you are entitled. Authorization to use or release your PHI is <u>in addition to</u> your consent to participate in this research study. However, you cannot participate in this research study if you do not authorize the use or release of your PHI.

7. How long will this Authorization last?

This authorization shall expire at the completion of the research project.

8. Will my health information be used for other purposes?

No

CONTACT PERSONS:

The principal and secondary investigator involved with the study, clinic doctors and nursing staff are available to answer any questions you may have about this study. If you have questions, contact *Sue Mlynarczyk, secondary investigator at (616) 391-3050.* Should you have any questions regarding your rights as a participant, you may call:

- Spectrum Health Research and Human Rights Committee Representative, Linda Pool at 616-391-1291/1299.
- Michigan State's University Committee on Research Involving Human Subjects (UCRIHS); Peter Vasilenko, PhD Chair at (517 -355-2180). Michigan State University, 202 Olds Hall, East Lansing, MI, 48824-1047; Email: ucrihs@msu.edu

CONSENT

Adolescent Assent: By signing this consent form and returning the required surveys and demographic sheet you are indicating your voluntary agreement to participate in this study.

_____

Printed Name of Adolescent

_____ ____/____/____

Signature of Adolescent Date

Parental Consent: By signing this consent form and HIPAA authorization, and initialing each page, you certify you have read this form, you have had the opportunity to ask questions about this study and this form, and you have received answers that fully satisfy those questions. You are voluntarily signing this consent form and HIPAA authorization as evidence of your decision to have your adolescent participate in this study and you are giving authorization for release of all of your adolescent's protected health information relative to this research. You are aware you may withdraw your consent and HIPAA Authorization at any time and your care will not suffer. You will receive a signed copy of this Research Informed Consent and HIPAA Authorization.

_____ ____/____/____

Signature of Parent (or legal guardian) Date

_____ ____/____/____

Signature of Person Obtaining Consent Date

_____ ____/____/____

Signature of Principal Investigator Date

Research Informed Consent and HIPAA Authorization/Consent for Release of Health Information for Research Purposes

PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

Principal Investigator: Dr. Robert Boger, Ph.D. Michigan State University
Secondary Investigator: Susan M. Mlynarczyk, RN. MSN. (Spectrum-health), PhDc, MSU

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publication regarding this study, your identity will not be released without your expressed consent.

We recognize that some of those who receive protected health information may not be required under federal regulations to keep your information confidential, so we cannot guarantee that your information will not be released or made available to another party once it leaves Spectrum Health. Therefore, we share this information only if necessary and we use all reasonable efforts to request that those who receive it take steps to protect your privacy.

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5. Can I stop my information from being used?

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If you decide to stop your participation in this study and stop the collection of your health information as well, you must send a notice to: *Dr. Boger or Sue Mlynarczyk, C/O Cook Research Department, 100 Michigan, NE, MC38, Grand Rapids, MI 49503.*

6. What if I do not authorize you to collect and release my health information?

If you decide not to authorize release of your health information as part of this study, your decision will in no way affect your medical care or cause you to lose any benefits to which you are entitled. Authorization to use or release your PHI is <u>in addition to</u> your consent to participate in this research study. However, you cannot participate in this research study if you do not authorize the use or release of your PHI.

7. How long will this Authorization last?

This authorization shall expire at the completion of the research project.

8. Will my health information be used for other purposes?

No

CONTACT PERSONS:

The principal and secondary investigator involved with the study, clinic doctors and nursing staff are available to answer any questions you may have about this study. If you have questions, contact *Sue Mlynarczyk, secondary investigator at (616) 391-3050.* Should you have any questions regarding your rights as a participant, you may call:

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- Michigan State's University Committee on Research Involving Human Subjects (UCRIHS); Peter Vasilenko, PhD Chair at (517 -355-2180). Michigan State University, 202 Olds Hall, East Lansing, MI, 48824-1047; Email: ucrihs@msu.edu

ADULT CONSENT

By signing this consent form and HIPAA authorization, and initialing each page, you certify you have read this form, you have had the opportunity to ask questions about this study and this form, and you have received answers that fully satisfy those questions. You are voluntarily signing this consent form and HIPAA authorization as evidence of your decision to participate in this study and you are giving authorization for release of all of your protected health information relative to this research. You are aware you may withdraw your consent and HIPAA Authorization at any time and your care will not suffer. You will receive a signed copy of this Research Informed Consent and HIPAA Authorization.

_____ ____/____/____

Signature of Adult Date

_____ ____/____/____

Signature of Person Obtaining Consent Date

_____ ____/____/____

Signature of Principal Investigator Date

APPENDIX H

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS

APPROVAL LETTERS

MICHIGAN STATE
UNIVERSITY

Initial IRB Application Approval

April 20, 2005

To: Robert Boger
3d Human Ecology

Re: **IRB # 05-237** Category: EXPEDITED 1-4, 2-5, 2-7
Approval Date: April 18, 2005
Expiration Date: April 17, 2006

Title: PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

The University Committee on Research Involving Human Subjects (UCRIHS) has completed their review of your project. I am pleased to advise you that **your project has been approved**.

The committee has found that your research project is appropriate in design, protects the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: UCRIHS approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure***.

Revisions: UCRIHS must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify UCRIHS promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with UCRIHS.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at UCRIHS@msu.edu. Thank you for your cooperation.

Sincerely,

Peter Vasilenko, Ph.D.
UCRIHS Chair

c: Sue Mlynarczyk
516 Greenbrier SE
Grand Rapids, MI 49546

OFFICE OF
RESEARCH ETHICS AND STANDARDS
University Committee on Research Involving Human Subjects
Michigan State University
202 Olds Hall
East Lansing, MI
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www.humanresearch.msu.edu
E-Mail: ucrihs@msu.edu

MICHIGAN STATE
UNIVERSITY

Revision Application Approval

May 1, 2005

To: Robert BOGER
3D Human Ecology

Re: **IRB # 05-237** Category: EXPEDITED 1-4, 2-5, 2-7
Revision Approval Date: **May 1, 2005**
Project Expiration Date: **April 17, 2006**

Title: PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

The University Committee on Research Involving Human Subjects (UCRIHS) has completed their review of your project. I am pleased to advise you that **the revision has been approved**.

Revision to include a change to the instruments, consent and subject incentive. The new consent document is to replace the current one. Second Investigator Sue Mlynarczyk (mlynarcs@gvsu.edu).

The review by the committee has found that your revision is consistent with the continued protection of the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: UCRIHS approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure***.

Revisions: UCRIHS must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify UCRIHS promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with UCRIHS.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at UCRIHS@msu.edu. Thank you for your cooperation.

Sincerely,

Peter Vasilenko, Ph.D.
UCRIHS Chair

c: Sue Mlynarczyk
516 Greenbrier SE
Grand Rapids, MI 49546

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MICHIGAN STATE
UNIVERSITY

Revision Application Approval

August 22, 2005

To: Robert BOGER
3D Human Ecology

Re: **IRB # 05-237** Category: EXPEDITED 1-4, 2-5, 2-7
Revision Approval Date: August 19, 2005
Project Expiration Date: April 17, 2006

Title: PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

The University Committee on Research Involving Human Subjects (UCRIHS) has completed their review of your project. I am pleased to advise you that **the revision has been approved.**

Revision to include a change to the consent. The new consent document is an addition to the current one.

The review by the committee has found that your revision is consistent with the continued protection of the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: UCRIHS approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure.***

Revisions: UCRIHS must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify UCRIHS promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with UCRIHS.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at UCRIHS@msu.edu. Thank you for your cooperation.

Sincerely,

Peter Vasilenko, Ph.D.
UCRIHS Chair

c: Sue Mlynarczyk
516 Greenbrier SE
Grand Rapids, MI 49546

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MICHIGAN STATE
UNIVERSITY

Renewal Application Approval

April 17, 2006

To: Robert BOGER
3D Human Ecology

Re: **IRB # 05-237** Category: EXPEDITED 2-5, 2-7
Renewal Approval Date: **April 15, 2006**
Project Expiration Date: **April 14, 2007**

Title: PARENTAL SUPPORT AND ADOLESCENT HEALTH MANAGEMENT OF DIABETES

The Institutional Review Board has completed their review of your project. I am pleased to advise you that the **renewal has been approved.**

The review by the committee has found that your renewal is consistent with the continued protection of the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure.***

Revisions: The IRB must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,

Peter Vasilenko, Ph.D.
SIRB Chair

c: Sue Mlynarczyk
516 Greenbrier SE
Grand Rapids, MI 49546

OFFICE OF REGULATORY AFFAIRS
Human Research Protection Programs

BIOMEDICAL & HEALTH INSTITUTIONAL REVIEW BOARD (BIRB)

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SIRB & BIRB: IRB@msu.edu
CRIRB: crirb@msu.edu

APPENDIX I

SPECTRUM HEALTH RESEARCH AND HUMAN RIGHTS COMMITTEE

APPROVAL LETTERS

Spectrum Health
BUTTERWORTH CAMPUS

100 Michigan Street NE Grand Rapids MI 49503-2560
616 391 1774 fax 391 2745

May 2 , 2005

Susan Mlynarczyk RN
516 Greenbriar Dr. SE
Grand Rapids, MI 49546

Dear Ms. Mlynarczyk:

By means of the expedited review process your project "Parental Support and Adolescent Health Management of Diabetes", protocol dated 05/02/05, informed consent form dated 03/11/05, was given approval by the Spectrum Health Research and Human Rights Committee.

Your approval period is from 05/02/2005 to 05/02/2006. The Spectrum Health number assigned to your study is 2005-090. Please use this number as a reference in all correspondence to the research office regarding your study.

Any changes made to the study, including informed consent changes, following this approval require submission in writing to the IRB and approval by the committee. Changes may not be implemented until approved by the IRB. Approval of your research means you are responsible for complying with all policies and procedures of the FDA, OHRP, HIPAA, Spectrum Health Hospitals, and the Spectrum Health Research & Human Rights Committee.

The FDA and this committee require you submit in writing a progress report to the committee by 04/01/2006. Your study cannot continue after 05/02/2006 until re-approved by the Spectrum Health Research and Human Rights Committee. You will need to apply for re-approval 4-6 weeks prior to that time if your study continues to be ongoing and/or patients continue to be followed, even if the study has closed to patient accrual. You must complete a study closeout form if your study has been completed, terminated, or if you are not renewing the study.

If you have any questions about the terms of this approval please phone myself or Tiffany VanTilburg at 616-391-1299.

Sincerely,

Jeffrey Jones MD
Chairman, Spectrum Health Research and Human Rights Committee

JSJ:vgb
c: file

Spectrum Health

100 Michigan Street NE Grand Rapids MI 49503-2560

September 6, 2005

Susan Mlynarczyk
516 Greenbriar Dr SE
Grand Rapids, MI 49546

Dear Ms. Mlynarczyk:

By means of the expedited review process the informed consent form for adult patients (dated 07/28/05) for your project "Parental Support and Adolescent Health Management of Diabetes", was given approval by the Spectrum Health Research and Human Rights Committee.

The Spectrum Health number assigned to your study is 2005-090. Please use this number as a reference in all correspondence to the research office regarding your study.

Any changes made to the study, including informed consent changes, following this approval require submission in writing to the IRB and approval by the committee. Changes may not be implemented until approved by the IRB. Approval of your research means you are responsible for complying with all policies and procedures of the FDA, OHRP, HIPAA, Spectrum Health Hospitals, and the Spectrum Health Research & Human Rights Committee.

The FDA and this committee, require you submit in writing a progress report to the committee by 04/01/2006. Your study cannot continue after 05/02/2006 until re-approved by the Spectrum Health Research and Human Rights Committee. You will need to apply for re-approval 4-6 weeks prior to that time if your study continues to be ongoing and/or patients continue to be followed, even if the study has closed to patient accrual. You must complete a study closeout form if your study has been completed, terminated, or if you are not renewing the study.

If you have any questions about the terms of this approval please phone myself or Tiffany VanTilburg at 616-391-1299.

Sincerely,

Jeffrey Jones MD
Chairman, Spectrum Health Research and Human Rights Committee

JSJ/vgb
c: file

Spectrum Health

Butterworth Campus
100 MICHIGAN STREET NE GRAND RAPIDS MI 49503-2560
616 391 1774 FAX 391 2745 *www.spectrum-health.org*

April 22, 2005

Sue Mylnarczyk
516 Greenbrier Drive SE
Grand Rapids, MI 49546

Dear Sue,

The Nursing Research Committee has completed the review of your research proposal, *"Parental Support and Adolescent Health Management of Diabetes"* at the April 19, 2005 committee meeting. I am pleased to inform you that your proposal has received approval pending receipt of the approval letter from Michigan State University.

Once your letter is received, you will be ready to proceed to the Hospital Research and Human Subjects Committee. Linda Pool has been provided with a copy of your proposal. She can be contacted at (391-1291) for arrangements related to the Hospital Research and Human Subjects Committee.

As per Nursing Research Committee policy, you will be assigned a sponsor who will serve as a resource to you during this study. I am happy to personally serve in that capacity. Please contact me at 391-2676 when you are ready to begin data collection, and keep me informed of your progress during the study.

Upon completion of your research study, we will look forward to an oral and /or poster presentation in a format appropriate to the topic and in timing with other educational offerings. We also encourage you to present your findings via conference presentations and publication.

Please feel free to call me if you have any questions or need further clarification. I can be reached at 391-2676.

Sincerely,

Jan Hodges

Jan Hodges, MSN, RN
Chair, Nursing Research Committee

C: Linda Pool

REFERENCES

REFERENCES

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