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# A SOCIAL ECOLOGICAL PERSPECTIVE ON DIABETES CARE: SUPPORTING ADOLESCENTS AND CAREGIVERS

by

# APRIL IDALSKI CARCONE, M.S.W.

# DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

## **DOCTOR OF PHILOSOPHY**

2010

MAJOR: SOCIAL WORK

Approved by:

Advisor

Date



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## **DEDICATION**

This dissertation research study is dedicated to my husband, Michael Carcone. His love and support guided me through this challenging process. I am forever grateful.

I would also like to dedicate this work to my daughter, Malina Carcone. Malina was born midway through my doctoral education and since her birth has provided the grounding and motivation to persevere. I hope I provide a role model for her own life and career aspirations.



#### ACKNOWLEDGMENTS

I wish to acknowledge Deborah Ellis, Ph.D. Deborah was my professional supervisor and mentor throughout my doctoral education. Deborah provided the data for the study as well as her professional support and guidance. Without her support this dissertation would not have been completed.

Arlene Weisz, Ph.D., was both my academic and dissertation advisor while in the doctoral program. I am certain that her advice and guidance helped smooth my path through my doctoral training. I appreciate her insight and thoughtfulness.

I feel fortunate to have had a dissertation committee that was characterized by a collegial and advisory spirit. My committee helped me to develop a study that is well-grounded in both science and social work. I hope that my future collaborations will be equally scholarly and productive.

I wish to extend special recognition to Thomas N. Templin, Ph.D. Tom took time out of his busy schedule to consult with me on my structural equation modeling analyses. This support came at a critical time in my dissertation work and moved the project toward its end.

Finally, I wish to also acknowledge al the faculty within the Wayne State University School of Social Work who provided support, guidance, and helped me learn the important lessons that will direct my future career.



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#### **CHAPTER 1 INTRODUCTION TO THE STUDY**

Living with diabetes is a daunting undertaking. Daily life is consumed with the demands of the multiple aspects of the diabetes management regimen. People living with diabetes must monitor their blood glucose level, self-administer insulin, and estimate the carbohydrate content of the food they eat multiple times each day. These tasks are complex and demanding, requiring daily motivation and self-control to maintain optimal illness management (Dovey-Pearce, Doherty, & May, 2007).

Adolescents with diabetes are doubly challenged. They must not only cope with the demands of the diabetes illness management regimen but also the normal developmental tasks of adolescence (Doherty & Dovey-Pearce, 2005). Typical adolescent developmental tasks can be delayed or compromised among adolescents with diabetes. For instance, adolescents with diabetes may not have the same degree of independence that their healthy peers enjoy due to parental concerns about their medical condition (Dovey-Pearce, et al., 2007). Conversely, illness management behaviors can be compromised by behavioral traits characteristic of adolescents. For example, adolescents often underestimate their own personal risks for poor diabetes management despite acknowledging the risks other adolescents with diabetes face (Delamater, 2007).

In recognition of the complexity of managing a chronic illness like diabetes during adolescence, there has been a call to include social workers and psychologists on multidisciplinary treatment teams (Delamater, 2007). Medical social workers, as members of multidisciplinary diabetes treatment teams, can promote a more holistic view of the adolescent with diabetes by providing information regarding the psychosocial factors impacting adolescents living with diabetes and extending treatment beyond the individual to include the family



(Thompson, Auslander, & White, 2001b). Social support for individuals with a chronic illness like diabetes is one such psychosocial factor. To this end, the goal of this proposed research study is to increase knowledge regarding the relationship between social support and adolescents' diabetes management and health status.

#### **Proposed Research and Study Aims**

This dissertation research study proposes a social ecological model of social support for adolescents' illness management behaviors. Four sources of social support spanning three social ecological systems within which adolescents with diabetes are embedded will be examined: 1) support provided to the adolescent from family located within adolescents' microsystems, 2) support provided to the adolescent from peers also located within adolescents' microsystems, 3) support provided to the adolescent's caregiver by other adults which may be located within adolescents' meso- or exosystems, and 4) support provided to the family unit from the medical care provider located within adolescents' mesosystems. In this model, support from the four social systems will be evaluated simultaneously to assess a comprehensive model of support for diabetes illness management and health status. A model examining social support in this manner has not been empirically tested.

To achieve this goal, a secondary data analysis will be conducted from an existing study dataset. The primary data were collected as part of an intervention study adapting Multisystemic Therapy (MST) to improve the illness management behaviors of adolescents with insulindependent diabetes in chronically poor metabolic control and their caregivers (Ellis, et al., 2005; Ellis, et al., 2008). These data are appropriate for testing a social ecological model of social support as the MST theoretical framework is grounded in Bronfenbrenner's social ecological model of behavior (Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 2009). Hence,



MST views behavioral problems, such as difficulty with diabetes management, as resulting from problems within and between the systems within which families are connected, which might include insufficient or ineffective social support.

Recruitment for the parent study was conducted at Children's Hospital of Michigan (CHM) in Detroit. The pediatric endocrinology clinic at CHM serves a primarily minority, low income population of children and families, a population that has largely been underrepresented in health care research and that has significant barriers to accessing health care (McQuaid, 2008). Interventions targeting African-American youth with diabetes are especially needed as these youth are at a higher risk for poor diabetes management and health outcomes (Delamater, et al., 1999). Hence, this study will target a group of adolescents who are at particular risk for poor health and face disparities in both health care research and health care delivery.

#### **Insulin-Dependent Diabetes**

Insulin-dependent diabetes (IDDM) is a chronic, incurable metabolic disorder affecting roughly 3.2 out of every 1,000 children under the age of eighteen in the United States and 5.6 of every 1,000 of those age twelve to seventeen (Lee, Herman, McPheeters, & Gurney, 2006). The number of children living with chronic illnesses is increasing due to advances in health care and technology (Light, 2001). As the rates of childhood obesity rise, the number of children with diabetes, especially type 2 diabetes, is increasing given the estimate that an obese child ( $\geq$ 95 percentile body mass index) is more than twice as likely to develop diabetes than a normal weight child (Lee, et al., 2006).

IDDM occurs when the pancreas entirely ceases to produce insulin, a hormone necessary for the breakdown of carbohydrates into glucose for use by the body's cells, or when the insulin produced by the pancreas can not be functionally utilized by the body (Bliss, 1982). Although



currently incurable, IDDM is treatable with a daily regimen of blood glucose monitoring, insulin administration, and dietary regulation of carbohydrate intake as well as regular exercise to control the amount of glucose in the bloodstream. Such illness management is complex and demanding, requiring daily motivation and self-control to maintain optimal metabolic (blood glucose) control (Dovey-Pearce, et al., 2007). Failure to comply with the daily care regimen leads to poor glucose control and places the individual at risk for a whole host of adverse short-and long-term complications including hospitalization for diabetic ketoacidosis, hypometabolic coma, stroke, nephropathy, retinopathy, neuropathy, cardiovascular disease, and amputation (Silverstein, et al., 2005). Even more frightening than this list of complications is the fact that the long-term complications associated with poor diabetes care can be detected as early as five years post-diagnosis (Silverstein, et al., 2005).

#### **Nature of Diabetes in Adolescence**

Adolescents are at particular risk for diabetes complications, both short- and long-term, for two primary reasons. First, the hormonal changes that occur during adolescence are linked to decreased insulin sensitivity which, in turn, can lead to deterioration in glucose control (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986; Moran, et al., 1999; Silverstein, et al., 2005). However, evidence exists that suggests adolescents' glucose levels remain elevated and peak around age 18 to 22, well after the onset of puberty and the hormonal changes that accompany puberty (Bryden, et al., 2001). Such evidence points to a second reason for the deterioration in glucose control during this time: psychosocial risks or vulnerabilities.

Psychosocial factors have been identified as the most important influences affecting diabetes management among children and adolescents (Delamater, 2007). Adolescents with diabetes report higher rates of internalizing behaviors (Bennett, 1994; Lavigne & Faier-Routman,



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1992), externalizing behaviors (Lavigne & Faier-Routman, 1992), eating disorders (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007), and overall adjustment problems (Lavigne & Faier-Routman, 1992) than their healthy counterparts and/or normal populations. In addition to causing behavioral and emotional distress, psychosocial vulnerabilities have been linked to poorer illness management, decreased metabolic control, and increased diabetes complications. For example, Bryden and colleagues (2001) found that adolescent psychological symptoms predicted adolescent health status. Similarly, Stewart, Rao, Emslie, Klein, and White (2005) found that the likelihood of diabetes-related hospitalizations among adolescents with type 1 diabetes increased when a clinical level of depression symptoms was reached. Protective factors, such as social support, may, therefore, decrease adolescent psychosocial vulnerabilities and improve illness outcomes.

#### **Social Support for Diabetes in Adolescence**

Cohen and Wills (1985) describe two theories of how social support impacts behavior. The main effects model of social support states that "a generalized beneficial effect of social support could occur because large social networks provide persons with regular positive experiences and a set of stable, socially rewarded roles in the community" (p. 311). This model suggests that social support would be related to adolescent well-being regardless of the particular characteristics of the adolescent (Hanson, Henggeler, & Burghen, 1987). Studies that have assessed overall or general social support to the adolescent from family or peers have linked social support to adolescent diabetes management. Therefore, there is some evidence for a main effect model of social support for adolescents with diabetes.

The majority of studies, however, overwhelmingly support the alternative, stress buffering, model of social support as a conceptual framework for understanding the impact of



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social support on diabetes management (DiMatteo, 2004; Gallant, 2003; Kyngäs, Hentinen, & Barlow, 1998). The stress buffering model of social support suggests that social support exerts a protective function under conditions of stress. The mechanisms by which stress is linked to health outcomes include changes in perceptions, disruption of biological functions, or behavioral changes affecting health, such as failures in self-management (S. Cohen & Wills, 1985). The failure in diabetes management mechanism is the focus of this study. Social support has been linked to diabetes health status through the protective function of better daily illness management behaviors (DiMatteo, 2004). This study will examine four sources of social support for adolescents' diabetes illness management and health status.

Social Support From Parents and Family. For children and adolescents, support received from their parents and families is the earliest and most crucial source of social support (Wysocki & Greco, 2006). Throughout adolescence, parental and family support for diabetes care decreases. This decrease occurs primarily as a function of age and markers of physical maturity (Palmer, et al., 2004), regardless of other indicators of adolescents' cognitive or emotional readiness to assume greater responsibility for their diabetes management (Anderson, 2003; Wysocki & Greco, 2006). Premature increases in adolescents' autonomy for diabetes management tasks are directly related to poorer illness management behaviors and poorer diabetes health status (Hsin, La Greca, Valenzuela, Taylor Moine, & Delamater, 2009; Wysocki & Greco, 2006). However, with few exceptions, the bulk of this research has been conducted with samples of adolescents representative of middle-upper socioeconomic status and majority racial backgrounds. This study will broaden the empirical literature to include adolescents of lower socioeconomic and minority racial status.

Social Support From Friends and Peers. At the same time that parental support is



diminishing, adolescents are expanding their social worlds and increasingly incorporating others, especially their peers, into their social support network (Fuligni & Eccles, 1993; Parker, Rubin, Erath, Wojslawowicz, & Buskirk, 2006). Although increased peer interactions and influence during adolescence are developmentally appropriate, for adolescents with chronic illness, peers could have either a supportive or detrimental effect on illness management behaviors. For example, some research has demonstrated how adolescents might compromise their illness management by failing to complete illness management tasks while in the company of their peers in an effort to conform to peers' normative expectations (Thomas, Peterson, & Goldstein, 1997). On the other hand, there is evidence that peer support can benefit adolescents' illness-related behaviors. For example, Bearman and La Greca (2002) found that adolescents' friends' support for blood glucose testing, one component of the diabetes regimen, was associated with increased blood glucose testing behavior. Similar to the research on parental and family support, the bulk of peer and friend support research has been conducted with adolescents of middle-upper socioeconomic and majority racial status. This study increases the scope of the empirical literature to include adolescents of lower socioeconomic and minority racial status.

Social Support for the Caregiver. Social support for the caregiver is a third source of social support impacting adolescents' diabetes. The theoretical mechanism of social support for the caregivers is that social support positively impacts adolescents' illness management by enhancing the caregivers' ability to provide support to their adolescent. A few studies have examined social support for the caregivers of adolescents with diabetes. However, the majority of research in this area has been conducted with caregivers of adolescents with chronic illnesses other than diabetes. Furthermore, this literature has primarily focused on how the demands of caring for a child with a chronic illness impact caregivers' own mental health outcomes. Only



one study was identified that examined the relationship between social support for the caregiver and adolescent illness management (Lewandowski & Drotar, 2007). In this study, support from the caregiver's spouse was directly related to adolescents' diabetes management such that greater levels of support were related to better illness management. Therefore, the proposed study will also extend empirical knowledge to include social support for caregivers of adolescents with diabetes and its impact on diabetes outcomes.

Social Support From the Medical Care Provider. A final source of social support examined in this study is social support from the medical care provider. Because diabetes is a chronic illness for which adolescents and their caregivers must engage in routine medical care, the relationship the family has with the medical care provider is paramount for effective illness management. Medical care providers might support adolescents' diabetes through two mechanisms. Emotional support from the medical care provider, such as empathy and praise, can increase adolescents' and their caregivers' confidence and ability to complete their illness management tasks. Medical care providers can also impact diabetes care directly by increasing families' access to resources necessary for illness management. However, there is little research examining the relationship between support from the medical care provider and diabetes management outcomes in children and adolescents. One qualitative study linked increased medical provider support with better illness management behaviors in a sampling of adults with diabetes (Thorne & Paterson, 2001). The proposed research will add to the empirical literature by examining social support from the medical care provider for adolescents with diabetes.

#### A Social Ecological Model of Social Support for Adolescents' Diabetes

In addition to examining the relationship between each of these social support areas and adolescents' diabetes outcomes, a goal of this research is to examine a model that evaluates the



relative contribution of all four sources of social support to adolescent illness management. This social ecological model of social support spans three systems. Social support to the adolescent from family and peers is located with adolescents' microsystems. Support from the medical care provider is contained within adolescents' mesosystem as adolescents and caregivers typically attend medical appointments together (however, in this study caregivers' perspectives are assessed). When caregivers identify persons living within the family home as their primary support person related to their adolescents' diabetes care, support for the caregiver from other adults taps the adolescents' mesosystems. A social ecological model fits with the multifaceted nature of social support as different sources of support uniquely contribute to illness management and health outcomes. Much of the research conducted has considered sources of support independently despite theoretical and empirical understanding and promotion of systemic perspectives.

A social ecological perspective is congruent with a social work perspective. Social workers strive to understand and support the individual from within his or her unique context (Auslander, Bubb, Rogge, & Santiago, 1993). Understanding how different sources of social support might unique contribute to improving outcomes for adolescents with diabetes is important for effective, targeted social work intervention.



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#### **CHAPTER 2 A REVIEW OF THE RELEVANT LITERATURE**

This chapter will review the literature on social support for adolescents with diabetes. The review will focus on four sources of support: support for the adolescent from family, support for the adolescent from friends, support for the caregivers of adolescents with diabetes, and support from health care providers. The chapter will conclude by describing how the research proposed in this dissertation will extend what is known about social support for adolescents with diabetes.

#### Parental and Family Support for Adolescents with Diabetes

Because children typically live at home with their parents, the earliest and, arguably, the most crucial source of social support for children with diabetes is that which they receive from their parents (Hanna, 2006; Wysocki & Greco, 2006). In childhood, parents of children with diabetes assume primary responsibility for all diabetes illness management behaviors, including insulin administration, blood glucose monitoring, and following dietary recommendations (Wysocki & Greco, 2006). However, as children mature into adolescents, or for those youth diagnosed with diabetes in adolescence, primary responsibility for diabetes management shifts from parents to the adolescents themselves (Wysocki & Greco, 2006) and, hence, support from parents assumes an important role.

While a shift in responsibility for diabetes care is necessary for adolescents to successfully transition to adulthood and independence, such transitions typically occur primarily as a function of age and pubertal status, versus other indicators of readiness to assume greater illness management responsibility (Palmer, et al., 2004), and in conjunction with decreases in parental support for adolescents' diabetes illness management (Anderson, 2003). Anderson et al. (1997) demonstrated that parental involvement in insulin and blood glucose monitoring is greater



in childhood (8-12 years) than in adolescence (13-17 years) regardless of the length of time the child had been diagnosed with diabetes. Skinner and colleagues found older adolescents to have less support from their parents for diabetes dietary management (Skinner & Hampson, 1998). Over a six months period, parental support for diabetes management specifically and family support in general decreased, especially among female participants (Skinner, John, & Hampson, 2000). Similarly, La Greca and Bearman (2002) found that younger adolescents report greater levels of support from their family across all diabetes illness management domains (insulin administration, blood glucose monitoring, diet, and exercise) as well as within the domain of emotional support for diabetes management, Hanson, et al. (1987) demonstrated that younger age of the adolescent, but not greater adolescent social competence, predicted greater parental support for diabetes. At the same time that parental and family support for diabetes is declining, empirical evidence suggests that adolescents' diabetes illness management behaviors deteriorate and their health status worsens.

**Relationship to Diabetes Outcomes.** The relationship between parental support for diabetes management and adequacy of adolescent diabetes management behaviors is well established. Empirical research has consistently linked lower levels of diabetes-specific social support to poorer illness management. This relationship is consistent whether social support from a single parent, both parents, or the family more broadly is considered.

Ellis, et al. (2007) examined the relationship between parental support for diabetes care and illness management within the context of parental monitoring. Ellis, et al.'s findings indicate that parental support for diabetes care was positively related to illness management behaviors such that greater support was associated with better illness management. Hanson et al. (1987)



examined the relationship between parental support, adolescent social competence, and illness management behaviors. In this study, the investigators found parental support significantly predicted illness management behavior even after the effects of age and social competence were controlled for. Helgeson, Siminerio, Escobar, and Becker (2009) linked both general and diabetes-specific parental support to illness management behavior. In summary, regardless of support type (either general or diabetes-specific) greater levels of parental support were related to better illness management behaviors.

Wysocki and Gavin (2006) examined illness-specific social support from fathers to adolescents with diabetes and five other chronic childhood illnesses. This study demonstrated that paternal support for diabetes care protected against declines in illness management behavior. Specifically, among youth who were 14 years or older, low to moderate levels of paternal support for diabetes care were associated with decreased illness management whereas those youth with high levels of paternal support maintained their levels of illness management.

Studies assessing social support for diabetes from the family more broadly have demonstrated a similar relationship to diabetes illness management. La Greca et al. (1995) demonstrated that higher levels of family support significantly predicted better illness management behavior among primarily White adolescents from two-parent families when controlling for the contribution of age and family cohesiveness. In a later study, La Greca and Bearman (2002) found specific support for insulin administration, blood glucose testing, and dietary recommendations from family members predicted illness management behaviors above and beyond age and family cohesiveness. In a recent study of Hispanic adolescents, lower family support for diabetes predicted poorer illness management behaviors; the only other significant predictor was the number of generations the adolescents' families had lived in the United States



(Hsin, et al., 2009).

Although Skinner and colleagues combined social support from family and friends, their research is consistent with the above research findings. Two studies conducted by this research group found that greater levels of support significantly predicted illness management behaviors specific to insulin administration (Skinner & Hampson, 1998) and diet recommendations (Skinner, et al., 2000).

The relationship between social support and diabetes health status is less consistent. Of the research studies that have examined the relationship between parental and family support for diabetes and health status, only one has demonstrated a relationship between family support and health status. In Thompson, et al. (2001b), family support, operationalized as living in a single-versus two-parent home, was associated with adolescent health status. Living in single-parent home, in conjunction with older age and African American ethnicity, predicted poorer diabetes health. In the studies reported by Hsin et al. (2009), Helgeson, Siminerio, et al. (2009), Ellis et al. (2007), Shroff Pendley, et al. (2002) and Hanson et al. (1987) social support from parents and family was unrelated to diabetes health status.

Two additional studies are worthy of mention as they fit with the above pattern of health status being unrelated to parental and family support. In the first, Wysocki and Gavin (2006), used a subjective measure of health status and number of hospital admissions and emergency room visits as a proxy measure of health status. Results from this study demonstrated no relationship between health status and paternal social support. In a study by Anderson, Brackett, Ho, and Laffel (1999), the investigators examined *unsupportive* parental behaviors before and after an intervention targeting family support behavior. Results indicated that although the intervention decreased unsupportive parental behaviors, this change was not significantly related



to diabetes health status; however a small sample size (N = 85) might have limited the investigators' ability to detect a relationship with health status.

Parental and Family Support as a Mediator or Moderator. Two studies examined how parental support mediates illness outcomes. Hsin et al. (2009) found social support mediated the relationship between adolescents' autonomy for their diabetes management and their actual illness management behaviors. In other words, among youth more independently responsible for their diabetes care, poorer illness management was attributed to lower levels of support for diabetes care. In their study examining the mediating role of parental support and adolescent social competence on the relationship between illness-related stress and diabetes health, Hanson et al. (1987) found parental support to be a significant predictor of illness management behavior. Adolescents who reported lower levels of parental support had poorer illness management behaviors. Parental support did not predict adolescent health status.

A third study investigating the role of parental monitoring on illness management behaviors found social support to be a moderator of illness outcome. Ellis et al. (2007) found social support partially moderated the relationship between parental monitoring and illness management behaviors and, indirectly, diabetes health status. In this study, youth reporting high levels of social support and high levels of parental monitoring had better illness management which related to better diabetes health.

**Methodological Issues.** A primary methodological concern identified in this review concerns the social support construct and its measurement. There were a number of studies that at first seemed to assess social support for diabetes care, but a careful review of the constructs measured revealed that these studies did not assess social support but rather some other dimension of family relationships. Two examples are Anderson, Brackett, Ho, and Laffel (1999)



and Wiebe, et al.(2005). In each of these studies parental involvement is framed as a dimension of social support for diabetes; however, the measures used actually assess responsibility for diabetes illness management tasks (e.g., who does what), a related but distinct construct.

A second methodological concern identified during this literature review is collapsing social support measures across sources and domains of support. Specifically, Skinner, et al. (2000) combined four measures of general and diabetes-specific social support from family and friends into a single index of social support. Although this index was predicative of multiple outcomes (adolescent depression, positive and total well-being, dietary illness management, and perceived control over one's illness), collapsing measures in this manner makes it impossible to distinguish which sources and types of social support are most relevant to particular outcomes. Similarly, separating illness management behaviors into discrete categories (e.g., insulin management versus dietary management), rather than assessing overall illness management, allowed differential relationships to social support to be identified (La Greca, et al., 1995; Skinner & Hampson, 1998).

Finally, there is some evidence that the type of respondent completing the instrument measuring social support has an impact on the findings. For instance, Ellis, et al. (2007) found adolescent-reported social support from caregivers was related to illness management behaviors, but this was not the case when caregiver-report of their own support was considered. Shared method variance might explain some of the association between adolescent-reports of these behaviors; however, maternal-reports were not similarly associated.

For adolescents, attempts by parents to provide support for diabetes management might have the potential to also increase parent-youth conflict, particularly if support is perceived as controlling or nagging (Anderson, 2003; Shroff Pendley, et al., 2002). Hence, this review now



turns to the effects of peer support.

## Friend and Peer Support for Adolescents with Diabetes

Typically, as parental support decreases, adolescents increasingly incorporate others, such as their peers, into their social support network (Fuligni & Eccles, 1993). This developmental trend also holds among adolescents with diabetes (13-17 years) who report greater peer support then children age 8-12 years (Shroff Pendley, et al., 2002). For adolescents with a chronic illness, support from close friends and the broader peer group represents an important source of social support that complements the support they receive from their parents and family (La Greca, Bearman, & Moore, 2002). While parents and family are a primary source of instrumental social support, friends and peers are a critical source of emotional support to adolescents with diabetes, increasing their capacity to handle the stresses of living with a chronic illness and their likelihood of performing the necessary management tasks (La Greca, et al., 1995; La Greca, et al., 2002).

In order for friends to be supportive of diabetes care, however, adolescents must disclose their diagnosis to their friends (La Greca, et al., 2002), something many adolescents choose not to do (Wysocki & Greco, 2006). Keeping their diagnosis a secret may undermine or eliminate the ability of friends and peers to provide support to adolescents living with chronic illnesses (La Greca, et al., 2002). Conversely, for "invisible" chronic illnesses such as diabetes where the illness might not be obvious to others, revealing one's diagnosis to friends and peers may have a negative impact on the perception of the adolescent and, consequently, social support received from friends and peers (La Greca, et al., 2002).

Peer pressure and the desire for social acceptance from peers might also detract from diabetes illness management behaviors (Wysocki & Greco, 2006). In an effort to fit in with their



broader peer group, adolescents with diabetes may neglect their illness management behaviors while in the company of friends and peers to avoid appearing different or calling attention to themselves (La Greca, et al., 2002). Hence, the importance of social support from friends and peers for chronic illness is still not fully understood.

Among adolescents with diabetes, friend and peer support varies by gender. Female adolescents report greater levels of social support from their friends in comparison to male adolescents (Helgeson, Lopez, & Kamarck, 2009; Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007; Helgeson, Reynolds, Shestak, & Wei, 2006). In a study by Helgeson, Lopez, and Kamarck (2009) the interaction of conflict and gender predicted diabetes health status such that female youth who reported greater levels of conflict within their friendship reported greater levels of depressive symptoms and poorer health status.

**Relationship to Diabetes Outcomes.** Although research has demonstrated that adolescents view their friends and peers as an important source of social support (La Greca, et al., 1995), empirical evidence linking such support to adolescents' illness management behaviors and health status is inconsistent. Illness management behavior was not related to friend support in La Greca et al.'s (1995) exploratory study of social support for diabetes illness management. Similarly, in Shroff Pendley et al.'s (2002) study of peer and family support, social support from peers for diabetes illness management was not associated with illness management behaviors or diabetes health status. The number of supportive peers, however, was related to health status.

Helgeson and colleagues found no relationship between general (not specific to diabetes) support from friends and either diabetes illness management behaviors or health status in three studies. The first study compared friendships of adolescents with diabetes and healthy



adolescents (Helgeson, Reynolds, et al., 2007). In this study, social support was not associated with diabetes illness management behaviors or health status. A second study, an investigation of the impact of friendship on psychological well-being and illness outcomes (Helgeson, Lopez, et al., 2009), did not find a relationship between support and health status. The third study, a longitudinal study to determine the predictors of health status during adolescence (Helgeson, Siminerio, et al., 2009), did find an association between support from friends and health status,. Greater support from friends was related to poorer health in youth 11-12 years old. Support from friends did not, however, predict health status over time.

In Bearman and La Greca's (2002) instrument development study for the Diabetes Social Support Questionnaire-Friends Version (DSSQ-Friends), overall diabetes-specific social support from friends did not predict illness management behavior beyond that which was explained by age. The individual correlation between support and illness management was not reported. Specific friend support for a specific illness management behavior, blood glucose monitoring, was, however, predictive of that behavior. Hains, Berlin, Davies, Smothers, Sato, and Alemzadeh (2007) used the DSSQ-Friends in their study of diabetes stress and friend support (described further below). The Hains group found social support from friends moderated the relationship between stress and health status, but there was no direct relationship between social support from friends and adolescents' health status.

As described in the parent and family support section above, a social support construct combining support from family and friends found support to be predictive of illness management behaviors. Specifically, greater levels of support significantly predicted insulin administration (Skinner & Hampson, 1998) and following diet recommendations (Skinner, et al., 2000).

Friend and Peer Support as a Mediator/Moderator. Hains, Berlin, Davies, Smothers,



Sato, and Alemzadeh (2007), in a study of diabetes stress and friend support for diabetes management, found the relationship between diabetes stress and health status was moderated by friend support. At average or higher levels of friend support, diabetes stress and health status were significantly related such that greater stress was associated with poorer health. Conversely, at low levels of support the relationship between diabetes stress and health status was not significant. The authors suggest that this counterintuitive finding might be explained by adolescents under the greatest stress having friends who are more supportive but that their friends' support might be ineffective at alleviating stress, underutilized by the adolescent, or maladaptive by encouraging poor diabetes-related behavior.

**Methodological Issues.** The use of general support measures in several studies (Helgeson, Lopez, et al., 2009; Helgeson, Siminerio, et al., 2009) might have contributed to those studies' inability to link support to illness-related outcomes. A second methodological concern relates to studies that fail to report a relationship between social support and illness management and/or adolescent health status. For example, Greco, Shroff Pendley, McDonell, and Reeves (2001) report on a pilot intervention for newly diagnosed adolescents with diabetes and their best friends. This study reported on pre- and post-intervention effects on social support but did not report the relationship of social support with illness management behaviors or health status at baseline or follow up. Similarly, La Greca, et al. (1995) examined illness management behavior but did not report on health status. These omissions make it challenging to understand the impact of social support from friends and peers on illness management behaviors and diabetes health status.

### Support for the Caregivers of Adolescents with Diabetes

This study will examine a third source of social support, support for the adolescent's



primary caregiver. The provision of social support to the caregivers of adolescents with diabetes is likely to impact adolescents' diabetes illness management behaviors and health status through two mechanisms. Instrumental support for caregivers, such as supporting specific illness management behaviors, is likely to increase the potential that adolescents actually complete the illness management behaviors necessary to care for their diabetes and, thereby, improve their health. Emotional support for the caregivers might have an indirect impact on adolescents' diabetes health status by enabling caregivers to be better able to support their children.

There has been little research examining how social support for the caregivers of adolescents with diabetes impacts diabetes outcomes. In comparison to immediately life-threatening chronic illnesses, such as cancer, or obviously debilitating illnesses, like juvenile rheumatoid arthritis or cerebral palsy, caregivers of adolescents with diabetes might not appear to be in as great a need of social support. Such a conception might have led to the support needs of these caregivers being overlooked. However, this is not the case. The caregivers of adolescents with diabetes report a need for social support in caring for their chronically ill child, especially when it comes to issues related to the transition of responsibility for illness management tasks to adolescents (Paterson & Brewer, 2009). Nonetheless the literature contains few studies examining social support for caregivers of adolescents with diabetes; hence, the literature review that follows is based primarily on caregivers of children and adolescents with chronic illness other than diabetes.

Previous research with other chronic illness populations has identified two correlates of caregiver support: illness severity and caregiver education. Greater illness severity was associated with lower levels of social support among caregivers of children with neurofibromatosis 1 (Reiter-Purtill, et al., 2008). Greater parental educational attainment was



related to greater social support in Florian and Krulik's (1991) study of caregivers of children with a number of different illnesses.

**Relationship to Diabetes Outcomes.** Research examining the role of social support for parents has primarily examined the impact of social support on parents' own outcomes. With the exception of one contradictory study, the literature shows a positive relationship between social support and caregiver outcomes. Two of these studies compared the caregivers of chronically ill children and those caring for healthy children.

Reiter-Purtill et al. (2008) studied the relationship between parental distress, social support, and family functioning between families living with a child with and without neurofibromatosis 1 (NFI). For mothers, social support was associated with maternal distress such that greater levels of social support were associated with less maternal distress. Similarly, Florian and Krulik (1991) linked social support to feelings of loneliness. Among mothers of healthy children and those with non-life threatening chronic illnesses, high social support was significantly and negatively related to loneliness. For mothers of children with life-threatening illnesses, lower levels of social support were associated with greater feelings of loneliness and more severe illness.

Horton and Wallander (2001) linked satisfaction with social support and the number of available support persons to maternal distress in a study of mothers of children with spina bifida, cerebral palsy, and insulin-dependent diabetes. Satisfaction with social support was negatively related to disability-related stress and positively related to hope. Satisfaction with social support and the number of available support persons predicted maternal distress and hope such that greater support predicted less distress and greater hope. However, in a study by Gerhardt and



colleagues (2003) of caregivers of children with juvenile rheumatoid arthritis (JRA), social support was unrelated to parental distress.

Only one study was identified that examined the relationship between social support for the caregiver and adolescent diabetes management (Lewandowski & Drotar, 2007). In this study, support from the mother's spouse was directly related to adolescents' diabetes management such that greater levels of support to the mother were related to better adolescent illness management.

**Evidence of a mediator/moderator relationship.** The studies described next examined whether social support functioned as a mediator or moderator of illness outcomes. Fuemmeler, Brown, Williams, and Barredo (2003) examined caregiver adjustment (the use of repressive adaptation, coping strategy) among families who had a child diagnosed with cancer. Results revealed that family support moderated adjustment such that those families who reported high levels of family support and high levels of repressive adaptation also reported less psychological distress. Family support did not moderate the relationship between caregiver adjustment and caregiver perceptions of children's adaptation; it did, however, account for some of the variance in children's adjustment problems.

Ievers, Brown, Lambert, Hsu, and Eckman (1998) studied family and social support in caregivers of children with sickle cell disease (SCD). This study found no evidence that social support moderated the relationship between parental distress and child behavioral problems. Noll, et al. (1994) examined social support as a moderator of parental distress and family conflict in a similar population of families caring for a child with SCD. Social support network size was correlated with perceived functional support; neither was correlated with other study variables. Hierarchical regression analysis indicated that family conflict was the only predictor of caregiver



distress. There were no differences between groups on social support; nor was there evidence for a main or buffering effect of social support on distress.

Studies including caregivers of children with diabetes have suggested that social support for the caregiver moderates maternal distress (Florian & Krulik, 1991; Horton & Wallander, 2001). Studies focusing on other chronic childhood illnesses have sometimes demonstrated a moderating effect of social support on caregiver distress (Fuemmeler, et al., 2003; Reiter-Purtill, et al., 2008) but at other times have not found social support to be a moderator of parental distress (Gerhardt, et al., 2003; Ievers, et al., 1998; Noll, et al., 1994).

**Measurement/Methodological Issues.** Research examining social support for the caregivers of adolescents with chronic illnesses, including diabetes, has two primary methodological issues. The first concerns the selection of respondents. The bulk of research examining social support for caregivers has focused primarily on mothers of chronically ill children. Although mothers might assume principal responsibility for childcare, including illness management, fathers also have an important perspective. Overlooking the perspective of fathers represents a significant gap in the social support research.

The second methodological concern relates to research design. Much of the research on social support for parents has focused on comparing the parents of chronically ill children with the parents of healthy children (Gerhardt, et al., 2003; Reiter-Purtill, et al., 2008). While such comparisons give insight into the differential risk associated with caring for a child with a chronic illness, the risk relative to different illnesses or even within illnesses as related to varying severity would be especially important for social workers and other interventionists.

### Support from the Health Care Provider

Despite theoretical interest in the topic, empirical research has not adequately addressed



the topic of social support from health care providers for adolescents with diabetes. This might be due in part to the controversy regarding whether health care providers provide social support. The crux of the argument is that social support is provided within the context of a personal relationship, which some have argued that health care providers do not have with their patients (Hupcey & Morse, 1997). Within the context of a chronic illness like diabetes, however, where patients visit their physician multiple times a year and have regular telephone contact between these visits, it might be argued that there is a relationship between the adolescent, the family, and the care team that extends beyond the typical patient-provider relationship.

Health care providers may provide support to adolescents with diabetes and their caregivers through the alleviation of diabetes-related stress and through a direct effect on illness management behaviors. One qualitative study, conducted with adults with diabetes, found functional, informational, and emotional support led to mastery of illness management behaviors (Thorne & Paterson, 2001). This research will add to the literature on this topic by examining social support from the health care provider for adolescents with diabetes.

Results from these four areas of research suggest that social support for adolescent chronic illness is important but the implications for illness management and illness outcomes are not fully understood. Much research has examined the role of family and peer support for adolescents and its impact on metabolic control through adherence behaviors; less research has, however, examined the impact of social support for the adolescent's caregiver on this process. Additional research is needed to clarify how different sources and types of support impact both illness management behaviors and illness outcomes. This study addresses this gap in the literature by examining adolescent's diabetes care behavior from a social ecological perspective.

**Proposed Study Aim and Hypotheses** 



The aim of this research study was to test a social ecological model of social support for adolescents' diabetes illness management behaviors. In this model, social support from four unique social systems within which adolescents with diabetes are embedded were evaluated simultaneously to assess a comprehensive model of support for adolescents' diabetes illness management and health status. The following hypotheses guided this investigation:

- H1: It was hypothesized that each source of social support would be a significant indicator of overall social support for adolescents' diabetes which, in turn, would be significantly related to adolescents' illness management behavior after controlling for the effects of adolescent, caregiver, and illness characteristics.
- H2: It was hypothesized that adolescents' illness management behaviors would mediate the relationship between social support and adolescents' health status.

#### **Significance for Social Work Profession**

Despite the extensive clinical involvement of social workers in the care of adolescents with diabetes and a seemingly obvious fit with social work values, empirical research examining social support for adolescents with diabetes from a social work perspective is lacking. Research in this area has been dominated by psychology, nursing, and medicine, disciplines with important but different perspectives. Social work has a strength-based, family-focused tradition that can not only inform clinical practice, but also promote the empowerment of adolescents with diabetes and their families.

Findings from this study will further the effectiveness of medical social workers by providing a more comprehensive view of the social ecology of social support for adolescents' diabetes and identifying specific social support intervention targets. Specifically, two sources of social support, support for the caregiver and support from the health care provider, have not been



extensively studied and, thus, the need for of interventions to strengthen these relationships is not known.

Finally, minority adolescents from low-income, single-parent families have largely been neglected by previous research. These youth deserve the same level of attention and intervention as mainstream, majority populations. As social workers it is our mission to advocate for the disenfranchised segments of the population.



#### **CHAPTER 3 THEORETICAL FOUNDATIONS**

This research study is grounded in the Social Ecological Model. This framework describes the unique social context in which adolescents are embedded and how this context might impact social support. This chapter provides an overview of this theory and discusses how it informs the proposed research study. First, however, an overview of the concept of social support is presented.

### **The Social Support Construct**

"Social support refers to social assets, social resources, or social networks that people can use when they are in need of aid, advice, help, assistance, approval, comfort, protection, or backing. It summarizes information that one is cared for, esteemed and valued, and part of a network of communications and mutual obligations" (Vedder, Boekaerts, & Seegers, 2005, p. 269).

This definition illustrates the multidimensional nature of the social support construct and highlights a major criticism of the social support literature: its imprecise definition of social support (Barrera, 1986). Underlying this complexity is the simple theme of social support as an interaction in which resources are exchanged (Shumaker & Brownell, 1984). Research examining social support for adolescents with diabetes has focused on three dimensions: the social network, enacted support, and perceived support (Hanna, 2006).

The social network refers to the structural aspects of social support which are typically defined as "a person's connections" and are generally quantified as the number of support persons or the physical distance between an individual and his support persons (Hanna, 2006). For adolescents, an index of the social network might also include the household structure, such as whether the adolescent lives in a single- or two-parent home (Thompson, et al., 2001b). Social network conceptions of social support generally assume that social networks are wholly beneficial, i.e., the greater number of support persons equates to a greater level of support, and


fail to consider negative aspects of relationships with different support network members (Hanna, 2006).

Enacted support is actual help an adolescent receives from support persons and is categorized by its various functions: affective, companionship, guidance, and aid (Hanna, 2006). Affective support refers to emotional support or nondirective guidance (Hanna, 2006). Affective support is generally characterized as "caring" through the provision of trust, empathy, and love (Tardy, 1985). Companionship or belonging is similar, but refers to specific aspects of emotional support that occur through positive social interactions (Hanna, 2006). Guidance and aid are the tangible aspect of social support. Guidance support refers to the provision of information or directive advice (Hanna, 2006). Aid is typically referred to as instrumental support or tangible assistance and implies the availability of physical or financial resources (Hanna, 2006). As evident from these descriptions, enacted support involves an interpersonal interaction of giving and receiving support; as such, it can be conceptualized from the perspective of the giver or receiver (Hanna, 2006).

Perceived support is the recipients' appraisal of the availability and satisfaction with support (Hanna, 2006). Perceptions of social support are by their very nature subjective. Hence, conceptualizing perceived support can be challenging as it may be perceived negatively when there is too little or too much support available, the intentions of the support provider are not perceived positively, or when the recipient's independence, self-efficacy, or self-esteem are adversely impacted (Hanna, 2006).

Conceptualizing social support involves considering not only the dimensions of social support but also the source of support. A social ecological model of social support for adolescents with diabetes suggests multiple sources of potential support both internal and



external to the family unit (Brown, 2002). Support for diabetes may be derived from relationships with parents and extended family members, friends and peers, teachers and school personnel, health care providers as well as members of the broader community. Research examining social support among adolescents with diabetes suggests that initially adolescents' parents and family are their primary source of social support (Hanna, 2006; Wysocki & Greco, 2006). As adolescents mature, their social world extends to include their close friends and the broader peer group as sources of social support (La Greca, et al., 2002). The mechanisms of support are discussed in the next section.

# The Social Ecological Model

**Ecological Theory.** The social ecological model is rooted in the ecological theory put forth by the American psychologist Urie Bronfenbrenner in the 1970s (Bronfenbrenner, 2008). Bronfenbrenner's ecological theory conceives of human development as influenced by a range of interacting influences that both support or stifle growth (Papalia, Olds, & Feldman, 2006). Two interdependent propositions outline the fundamental framework of the ecological theory.

Proposition one states "especially in its early phases, and to a great extent throughout the life course, human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate environment" (Bronfenbrenner, 2008, p. 4). The emphasis here is that the interactions between an individual and his environment are reciprocal (Rathus, 2006). Bronfenbrenner further specifies that these proximal interactions must occur regularly over an extended period of time to effectively shape the individual. An example of these processes is the interaction between a parent and a child or between a teenager and his peers.



Proposition two defines the individual's ecological context as unique. "The form, power, context, and direction of the proximal processes effecting development vary systematically as a joint function of the characteristics of the developing person, of the environment – both immediate and more remote – in which the processes are taking place, and the nature of the developmental outcomes under consideration" (Bronfenbrenner, 2008, p. 4). Hence, each individual's characteristics interact uniquely with his environment, creating a developmental context that is specific to that individual. This proposition helps to explain the differing developmental trajectories of individuals who may share personal and/or environmental characteristics.

Ecological theory conceives of the individual as being located centrally within a series of nested structures (Bronfenbrenner, 2008) or interlocking contextual systems (Papalia, et al., 2006). Figure 1 provides an illustration of Bronfenbrenner's ecological model.

Beginning at the individual, the innermost environmental structures that comprise the setting in which the individual lives are called microsystems (Bronfenbrenner, 2008). Microsystems consist of an individual's proximal transactional experiences with family, friends, teachers, and others with whom an individual has regular, ongoing interaction. These experiences are, in accordance with proposition one, bidirectional and include patterns of activities, social roles, and interpersonal relationships in which an individual personally functions day-to-day. Examples of microsystem experiences include being a student in high school, the oldest child of first generation immigrants, or a bagger at the local grocery store.

Initially an individual's microsystem is small, but as children develop their microsystem





*Figure 1*. The Social Ecological Model

grows, incorporating greater numbers of people (Rathus, 2006). The connection or interaction between two or more microsystems is a mesosystem (Bronfenbrenner, 2008). Examples of mesosystem connections are the relationship between an adolescent's parents and teachers or an adolescent's peers and religious organization. Mesosystems can illustrate different aspects of an individual's personality or behavior in their different interactions and responses in different contexts. As youth move through adolescence and their social worlds expand so does their mesosystem connections.



Moving outside of the individual's proximal interactions, an exosystem exists when two or more settings are connected but at least one of the settings does not include the individual. Therefore, the influence of the exosystem upon the individual is indirect (Bronfenbrenner, 2008). For illustration, consider the impact of the parental work microsystem. While the adolescent does not directly interact with his parent's place of employment, he is still affected by the parent's work microsystem through the parent's work hours, wages earned, and work-related stress.

Moving even further from the individual's microsystems, the broader cultural context makes up the macrosystem (Bronfenbrenner, 2008). Macrosystems are characterized by the dominant culturally specific practices, like beliefs, customs, and life styles that filter down through the typical exo-, meso-, and microsystems. For instance, state and federal legislation establish a moral code to which all citizens in a society must adhere. Or, the practice of living with only the nuclear family versus members of the extended family is a culturally determined practice.

A final contextual factor considered by ecological theory is time, referred to as the chronosystem (Bronfenbrenner, 2008). Ecological theory recognizes that micro-, meso-, exo-, and macrosystems are not static. As such, change or consistency over time and across the systems within which an individual is embedded has relevance for that individual's development. Take, for example, the current economic crisis. Adolescents graduating from Michigan high schools this year may be more likely to leave the state in search of job opportunities than those youth who graduated ten years ago.

Adapting the Ecological Model to Chronic Health Conditions. Bronfenbrenner's ecological model has been utilized to understand the impact a child's chronic illness has on the family (Brown, 2002; Kazak, 1997). Scholarly writing on this topic has emphasized the



reciprocal nature of chronic illness as well as the multiple systems impacting and impacted by day-to-day living with a chronic illness. The importance of both intra- and extrafamilial factors has been empirically supported in the literature (Naar-King, Podolski, Ellis, Templin, & Frey, 2006; Shroff Pendley, et al., 2002).

The social ecology of a family caring for a child with a chronic illness is largely shaped by the illness. Illness-specific microsystemic influences include the nature of the child's chronic illness and its impact on the child and other members of the family, including the parents and siblings (Brown, 2002). For a child with diabetes, the prognosis is promising. With adequate illness management, a child with diabetes can live a fairly normal life, participating in many of the same activities in which his peer group engages. However, for a child who does not perform his illness management behaviors adequately, living with diabetes can be difficult because there are very serious short- and long-term complications associated with poor illness management (see pages 3-4 of the introductory chapter for a more detailed discussion of diabetes complications).

The daily life of the family of a child living with diabetes is also impacted by the illness. New caregiving demands are thrust upon the parents and sometimes also upon the siblings of a child with a chronic illness (Loos & Kelly, 2006). The family's daily routine often changes to accommodate the illness management behaviors necessary to adequately care for the child's diabetes. Such accommodations impact the parents' as well as siblings' routines. For example, the parents of a child with diabetes might expect the sibling to become involved in the day-today care of the child with diabetes or the sibling might feel that chronic illness presents opportunities for the child with diabetes to have special privileges, such as staying up later or having special treats (Loos & Kelly, 2006). As such, it is not surprising that the siblings of



children with chronic illness are at an increased risk for adjustment problems (Bellin & Kovacs, 2006). The family may experience financial consequences of having a child with diabetes, because even with medical insurance the cost of medical supplies can be significant. As such caregivers of chronically ill children in lower income families experience greater levels of stress (Canning, Harris, & Kelleher, 1996).

The relationship between a child and his peers is also impacted by diabetes. A child with diabetes might be reluctant to reveal his diagnosis of diabetes with his peers or include friends in diabetes illness management tasks out of fear of stigma (Buchbinder, et al., 2005). Similarly, a child with diabetes might be disinclined to complete his diabetes care when in the company of his peers in an effort to conform to social norms, especially when the child perceives his peers as unsupportive of the illness or illness management tasks (Wysocki & Greco, 2006). Conversely, peers represent an important source of social support for a child with a chronic illness such as diabetes (Brown, 2002). Being able to share a group identity that promotes health and well-being, such as being an athlete, and having supportive friends both increases adaptation to the illness and improves illness management behaviors (La Greca, et al., 2002).

Living with a chronic illness also impacts the mesosystems of the family's social ecology. Of primary importance is the relationship a family has with the child's medical care providers (Brown, 2002). The relationship the family has with the medical care providers impacts the amount of information that both parents and health care providers have when making decisions about a child's illness and the treatment options. For example, health care providers might overor under-estimate the degree to which parents are involved in the daily illness management regimen if there is not a pattern of open communication between the parents and providers (Buchbinder, et al., 2005).



Other important mesosystem connections include the connections the family has to extended family and alternative caregivers. Extended family members are the greatest source of both supportive and nonsupportive illness-related behaviors (Patterson, Garwick, Bennett, & Blum, 1997). The extent to which extended family members can support the caregiving demands of caring for a child with diabetes, such as being educated and informed about the illness management behaviors required to care for the child's diabetes, has a direct impact on the child and family's adjustment (Brown, 2002). Finally, teachers and school personnel play an important role in the life of a child with diabetes, as illness management behaviors must be attended to during the school day. Like the extended family members and alternative caregivers, the degree to which teachers and school personnel are educated and informed about the illness management behaviors required to care for the child's diabetes during the school day directly impacts the child's diabetes during the school day directly impacts the child and family's adjustment (Brown, 2002).

Macrosystem influences impacting the life of a child with diabetes include the family's culture and beliefs (Brown, 2002). One example of how a family's culture and belief system impacts a child living with diabetes relates to caregivers' beliefs about parenting and monitoring of their children's behavior. Parental monitoring might increase or decrease the likelihood that adolescents with diabetes complete their illness management tasks (Ellis, et al., 2007). Caregivers who are low monitors might have children who avoid their self-care without detection; whereas children in families who are high monitors may be more likely to complete their illness care because their caregivers are following up on these tasks.

#### A Social Ecological Model for the Study of Social Support for Diabetes

This study examines how targeted social support from different sources within an adolescent's social ecology is related to a specific stressor, diabetes. Figure 2 presents the



conceptual model developed for the study. In this model, adolescents' diabetes outcomes, illness management behavior and health status, are conceptualized as being affected by four social support systems: social support for the adolescent from family, social support for the adolescent from friends, social support for the adolescent's caregiver, and social support from the health care provider.



# Figure 2. Conceptual Model of Social Support for Adolescents' Diabetes Management

As depicted in Figure 2, social support from all four sources is proposed to have a direct impact on adolescents' illness management behaviors and, through illness management, an indirect effect on diabetes health status. The hypothesis is that as support increases illness management behaviors improve, which, in turn, has a beneficial impact on health. Social support



provided to the caregiver also impacts support to the adolescent from family. The hypothesis is that as social support for the caregiver increases so does adolescents' social support from family.

The demographic characteristics of both the adolescents and their caregivers are hypothesized to impact their receipt of social support and the adolescents' illness management behaviors. For example, adolescents' social support from family and friends is hypothesized to vary by age, whereas support for the caregiver might vary by household structure, i.e., singleversus two-parent families. For adolescents, demographic characteristics are hypothesized to have a direct impact on their health. Specifically, African American adolescents are expected to have poorer health status regardless of other study variables.

This conceptual model represents a novel approach to understanding social support for diabetes management and health. A framework such as this has not been conceptualized or empirically tested in the social work or broader chronic illness literature. Rather, previous research has focused primarily on social support provided to the adolescent from family and friends. However, the social ecological model demonstrates that there are other important social support systems in which adolescents and their families are embedded that may impact adolescents' illness management and their health status. Thus, this study will expand understanding of how two understudied sources of social support, support for the adolescent's caregiver and support from the health care provider, are related to adolescent illness management and health status.



### **CHAPTER 4 METHODOLOGY**

In this chapter the methodology of the proposed research as well as the methodology of the parent study is discussed. The study design, sampling, participants, data collection procedures, instrumentation, and data analysis plan will be discussed in detail. The chapter concludes with a discussion of the implications this work has for the social work profession.

#### **Study Design**

This research study is a secondary analysis of baseline data collected for an intervention study. The parent study is a randomized, controlled, repeated measures design testing the efficacy of Multisystemic Therapy (MST) compared to a telephone support intervention to improve illness management behavior among high-risk adolescents with insulin-managed diabetes (Ellis, et al., 2006). A cross-sectional design using baseline data only was selected, as these data were collected prior to the randomization of study participants to intervention arms or the initiation of the treatment interventions. The follow up data were rejected for this analysis due to the fact that it reflects the effects of the MST intervention which directly targeted social support amongst other factors influencing adolescent illness management behavior.

## Sample

**Selection.** The study sample will consist of adolescents with insulin-managed diabetes (type 1 or type 2) who have a history of chronically poorly controlled diabetes. Participants were a convenience sample recruited from the diabetes clinics run by the Department of Pediatrics at the Children's Hospital of Michigan (CHM)/Wayne State University School of Medicine (WSU). WSU is an excellent setting for research, because in addition to being the largest urban medical school in the country, WSU's academic mission includes a focus upon health problems that disproportionately affect minorities.



Participants with either type 1 or type 2 insulin-managed diabetes were eligible to participate in the parent study because management of both types of diabetes includes taking insulin daily, testing blood glucose multiple times per day, and managing diet. The focus of the treatment intervention was to improve health status via improved illness management behaviors. Additional support for the inclusion of both adolescents with type 1 and type 2 is also provided by recent studies suggesting that traditional diabetes typologies are considerably more difficult to apply to minority youth and that "intermediate" types are common (Libman, Pietropaolo, Arslanian, LaPorte, & Becker, 2003; Lipton, et al., 2005). Minority youth represented 78.2% (104) of the study sample.

Participation in the primary study was restricted to adolescents who were in chronically poor diabetes health. Health status for adolescents with diabetes is evaluated with a particular measure of metabolic control, hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>; described in more detail below in the instrument section) which provides an assessment of average blood glucose levels in the preceding 2-3 months. For the purpose of the parent study, chronic poor control was defined as HbA<sub>1c</sub> that is greater than or equal to 8% currently and on average over the 12 months prior to study entry. Additional eligibility criteria included being between 10 and 17 years of age, residing within the metro Detroit tri-county area (Wayne, Oakland, or Macomb counties), and having written English language fluency. Participants were not selected based on race, ethnicity, or gender. However, African American adolescents are at increased risk for poor diabetes health (Auslander, Thompson, Dreitzer, White, & Santiago, 1997; Delamater, et al., 1999) and, as mentioned above, represent a majority of the participants given this fact and the location of the recruitment site.



To increase external validity, exclusion criteria were minimal. Participants with comorbid mental health problems, such as ADHD, conduct disorder, depression, eating disorder, or anxiety disorder, were not excluded from the study with the exception of participants with thought disorders (for example schizophrenia and other psychosis), suicidality, or homicidality. Adolescents with severe psychosis or current suicidal ideation were excluded because these disorders often require treatment strategies beyond the scope of the intervention, i.e., inpatient hospitalization or residential placement. Adolescents with moderate or severe mental retardation were also excluded due to their inability to adequately participate in the interventions as well as an inability to complete research measures. Adolescents with mild learning disabilities and/or mild developmental delay were included and additional assistance with the completion of research measures was provided where necessary, e.g., defining difficult words or reading items. Similarly, co-morbid physical health problems were not an exclusion criterion; however, if a potential participant had another chronic medical illness, such as cystic fibrosis, that altered their diabetes management behaviors substantially from that of most children with diabetes, they were excluded.

**Characteristics.** The study sample is 146 adolescents and their primary caregivers. Table 1 presents the demographic profile of the adolescent participants. Adolescents were mostly African American (77.4%, N=113), the remaining participants were White (19.9%, N = 29), Bi-Racial (1.4%, N = 2), Latino (0.7%, N = 1) and "Other Race" (0.7%, N = 1). Just over half of the adolescent participants were female (56.2%, N=82). At the time of study entry, adolescents were 14.2 (S.D. = 2.29) years old on average and ranged from 10.0 to 18.0 years of age. Adolescents were between the 4<sup>th</sup> grade and the 1<sup>st</sup> year of college at study entry; however, the majority were



in middle,  $6^{th}$  through  $8^{th}$  grades, (43.8%, N = 64) and high school,  $9^{th}$  through  $12^{th}$  grades, (44.5%, N = 65).

The majority of adolescents had type 1 diabetes (88.4%, N = 129). At the time of their diagnosis with diabetes, adolescents were 9.5 (S.D. = 3.77, Minimum = 1.0, Maximum = 16.5) years old on average. The mean duration of illness was 4.7 (S.D. = 3.04, Minimum = 0.5, Maximum = 16.0) years. Adolescents were on four different insulin regimens. Nearly one-third, 27.4% (40), of the adolescents were on a conventional mixed injection regimen. This regimen is the traditional insulin regimen; it consists of two or three injections of mixed short- and intermediate-acting insulin daily, requires strict adherence to a prescribed meal plan, and a tightly scheduled care routine. Over half, 56.2% (82), were on a basal-bolus injection regimen. This intensive insulin regimen demands less strict adherence to a prescribed meal plan and care schedule, however, requires greater skill with blood glucose testing and carbohydrate counting and more frequent insulin injections. Eighteen adolescents, 12.3%, were on an insulin infusion pump. An insulin infusion pump most closely mimics the body's natural release of insulin into the blood stream; however, it requires mastery of blood glucose testing and carbohydrate counting. Six adolescents, 4.1%, were on a basal injection only regimen. These adolescents had type 2 diabetes for which one injection of insulin each day was sufficient to maintain their blood glucose levels.

The adolescents' primary caregivers were primarily biological parents, 93.2% (136), one (0.7%) was a step-parent, three (2.1%) were adoptive parents, three (2.1%) were legal guardians, and three (2.1%) were some "other" relationship. Like the adolescents, the majority of the caregivers were African American (77.4%, N=113), 21.9% (32) were White, and 0.7% (1) was Bi-Racial. The majority were female, 91.1% (133) and the average age of the caregivers was



Table 1	
Adolesce	nt Characteristics

Characteristic	Distribution*		
Race or Ethnicity			
African American	77.4% (113)		
White/Caucasian	19.9% (29)		
Bi-Racial	1.4% (2)		
Latino	0.7% (1)		
Other Races	0.7% (1)		
Gender	5( 00/ (00)		
Female	56.2% (82)		
Male I F /	43.8%(04) $14.2 \pm 2.20$		
Age at Study Entry Grade	$14.2 \pm 2.29$		
4 <sup>th</sup> grade	4.1% (6)		
5 <sup>th</sup> grade	6.8% (10)		
6 <sup>th</sup> grade	13.7% (20)		
7 <sup>th</sup> grade	15.8% (23)		
8 <sup>th</sup> grade	14.4% (21)		
9 <sup>th</sup> grade	12.3% (18)		
10 <sup>th</sup> grade	11.0% (16)		
11 <sup>th</sup> grade	15.1% (22)		
12 <sup>th</sup> grade	6.2% (9)		
1 year of college	0.7% (1)		
Diabetes Type			
Type 1	88.4% (129)		
Type 2	11.6% (17)		
Age at Diagnosis	$9.5 \pm 3.77$		
Duration of Illness	$4.7 \pm 3.04$		
Prescribed Insulin Regimen			
Conventional Mixed Injections	27.4% (40)		
Basal-Bolus Treatment – Injections	56.2% (82)		
Insulin Infusion Pump	12.3% (18)		
Basal Injection Only	4.1% (6)		

\*% (N) or mean  $\pm$  standard deviation

41.4 (S.D. = 7.89). Just over forty percent of the caregivers were married or living with a partner,

41.1% (60), while the greater proportion were single, 58.9% (86).

As far as education, 15.7% (23) had less than a high school education, 35.6% (52) had a high school education, 12 years of school, 35.6% (52) reported 1-3 years of college, and 12.3% (18) reported 4 or more years of college. Nearly half of the participants (48.6%, N = 71) reported annual incomes less than \$30,000 per year, while 51.4% (N = 75) reported annual incomes of \$30,000 a year or greater. Sixty-one percent (61.0%, N = 89) were employed outside the home. The modal number of dependents that caregivers reported was four, 21.9% (32), although this number ranged from 0 to 9.

**IRB.** The parent study protocol was approved by the Wayne State University Human Investigation Committee (WSU HIC), protocol #067206MP4F, *Adherence to IDDM Regimen in Urban Youth*, Deborah Ellis, Ph.D., Principal Investigator. The parent study protocol is currently active. The protocol for this secondary data analysis study received a waiver of consent from the WSU HIC Chairperson; hence, the study was exempted from review. The Protocol Summary Form as well as the Concurrence of Exemption is attached in Appendix B. Risk to participants relative to the proposed secondary data analysis is minimal as the study investigator will not have access to information that could be used to identify the participants.

**Informed Consent.** All caregiver participants provided informed consent using WSU IRB approved informed consent forms at the time of their recruitment into the parent study. Adolescent participants 13 years and older provided informed assent using WSU IRB approved informed assent forms at the time of their recruitment into the primarily study; participants under the age of 13 provided verbal assent to the study recruiter. This documentation is maintained in the research offices of the parent study principal investigator.

### **Data Collection Procedures**

To increase participation and avoid barriers, such as a lack of transportation or



Table 2

Caregiver Characteristics

Characteristic	Distribution*		
Relationship To Adolescent			
Biological Parent	93.2% (136)		
Step-Parent	0.7% (1)		
Adoptive Parent	2.1% (3)		
Legal Guardian	2.1% (3)		
Other	2.1% (3)		
Race Or Ethnicity			
African American	77.4% (113)		
White/Caucasian	21.9%(32)		
Gender BI-Kaciai	0.7% (1)		
Female	91 1% (133)		
Male	8.9% (13)		
Age	$41.4 \pm 7.89$		
Grade			
1 <sup>st</sup> Grade	0.7% (1)		
10 <sup>th</sup> Grade	6.8% (10)		
11 <sup>th</sup> Grade	8.2% (12)		
12 <sup>th</sup> Grade	36.3% (53)		
1 Year Of College	8.9% (13)		
2 Years Of College	19.9% (29)		
3 Years Of College	6.8% (10)		
4 Years Of College	7.5% (11)		
5 Years Of College	0.7% (1)		
6 Years Of College	2.1% (3)		
11 Years Of College	2.1% (3)		
Marital Status			
Married To Mother/Father Of This Child	23.3% (34)		
Married But Not To Mother/Father Of This	9.6% (14)		
Child			
Single And Living With A Partner	5.5% (8)		
Divorced And Living With A Partner	2.7% (4)		
Single Or Widowed	34.2% (50)		
Divorced	24.7% (36)		
Annual Income			
Less Than \$10,000	18.5% (27)		
\$10,000 To \$19,999	15.1% (22)		
\$20.000 To \$29.999	15.1% (22)		



Characteristic		Distribution*		
	15.8% (23)			
	\$40,000 To \$49,999	9.6% (14)		
	6.2% (9)			
	4.8% (7)			
	2.1% (3)			
	2.7% (4)			
	3.4% (5)			
	\$100,000 Or More	6.8% (10)		
Caregiver Employment St	atus			
	No	39.0% (57)		
	Yes	61.0% (89)		
Number Of Dependents				
	0	0.7% (1)		
	2	18.5% (27)		
	3	27.4% (40)		
	4	21.9% (32)		
	5	15.8% (23)		
	6	4.8% (7)		
	7	5.5% (8)		
	8	4.8% (7)		
	9	0.7% (1)		

\*% (N) or mean  $\pm$  standard deviation

childcare, all data collection occurred in the family's home. Questionnaire data were collected from both the adolescent and the adolescent's primary caregiver. The primary caregiver is selfdefined by the family and is the person who helps the adolescent the majority of the time with managing diabetes. Caregivers and adolescents completed their data collection in separate rooms whenever possible. The data collector was blind to participants' randomization status; in addition, randomization occurred after baseline data collection, thus, any accidental un-blinding that might have occurred would not affect the data analyzed for this study.

# Instruments



The instruments used in this study are described below. For each questionnaire, the content and format of questions are detailed, scoring rubrics are explained, and available psychometric data are presented. For objective data, the procedures for collecting and handling the data are detailed and any scoring procedures are presented. Appendix C contains copies of all the instruments described in this section.

**Social Support.** The independent variable in this study is social support for diabetes. Four sources of social support are assessed: diabetes-specific support for the adolescent from family, diabetes-specific support for the adolescent from friends, diabetes-specific support for the caregiver, and support from the health care provider.

Diabetes Social Support Questionnaire-Family (DSSQ- Family). The DSSQ-Family measures adolescents' perception of enacted social support from family for diabetes management tasks and their satisfaction with this support (La Greca & Bearman, 2002). The DSSQ-Family assesses five areas important for diabetes illness management. In the parent study, the dietary items were excluded because they are not relevant for adolescents on intensive insulin therapy regimens, the current standard of care for diabetes illness management in the CHM diabetes clinics. Thus, a total of 32 family support questions are asked of adolescents: 8 questions related to insulin administration, 12 questions assessing blood glucose testing, 7 questions about exercise, and 5 questions querying emotional support. Each question is presented using a two-part Likert scale format. The first part of the question asks "How often does your family..." do each of the 32 supportive behaviors, to which adolescents may respond "never (0), less than two times a month (1), twice a month (2), once a week (3), several times a week (4), or at least once a day (5)." The second part of the question asks the adolescent to rate the supportiveness of the behavior queried, "How supportive (helpful) is this to you?", using a 3-point Likert scale, "not at



all, somewhat, or very".

An individualized scoring strategy was utilized in this study (La Greca & Bearman, 2002). Individualized scoring adjusts the frequency of each supportive behavior with the adolescent's perception of supportiveness for each behavior, i.e., the frequency of each behavior is multiplied by the perceived supportiveness. The mean of these adjusted scores across all items is the total individualized summary score which range from 0 to 15. Higher scores on each of these domains reflect greater levels of perceived support.

In the instrument validation study, La Greca and Bearman (2002) reported the psychometric properties of the DSSQ-Family. Internal consistency for the total individualized summary score was .98. In this study, Cronbach's alpha reliability was .94 indicating good internal consistency. La Greca and Bearman also found the total individualized summary score to have good concurrent validity as indicated by significant associations with general measures of family emotional support and cohesiveness. Discriminant validity was supported by the lack of association with friend support and family conflict. The DSSQ-Family also demonstrated predicative validity. The individualized total support score predicted illness management behaviors. Independent researchers have confirmed that the DSSQ-Family has content and face validity (Hanna, 2006).

*Diabetes Social Support Questionnaire-Friends (DSSQ- Friends).* The DSSQ-Friends is a diabetes-specific social support measure measuring friend support for diabetes management tasks that parallels the DSSQ-Family (Bearman & La Greca, 2002). As such, the DSSQ-Friends assesses five areas of diabetes care: insulin administration, blood glucose testing, meals, exercise, and emotional support. The dietary items were excluded from this measure as they were determined to be not relevant for adolescents on intensive insulin therapy regimens, which are



the current standard of care for diabetes illness management in the CHM diabetes clinics. The DSSQ-Friends asks adolescents 15 questions about support adolescents receive from their friends: 2 are about insulin administration, 5 pertain to blood glucose testing, 4 relate to exercise, 3 tap emotional support, and a final question asks "how many of you friends know you have diabetes?". Each question is presented using a two-part Likert scale format. The first part of the question asks "How often do your friends..." do each of the 14 supportive behaviors, to which adolescents may respond "never (0), less than two times a month (1), twice a month (2), once a week (3), several times a week (4), or at least once a day (5)." The response scale for the question about the number of friends who know the adolescent has diabetes is "none, only my best friend(s), some friends, and most/all". The second part of the question asks the adolescent to rate the supportiveness, "How supportive (helpful) is this to you?", for each of the 14 behaviors as well as the number of friends who know the adolescent has diabetes using a 3-point Likert scale, "not at all, somewhat, or very".

The same scoring strategy was used with the DSSQ-Friends as with the DSSQ-Family (Bearman & La Greca, 2002). The total individualized summary score was calculated by taking the average of all the adjusted item scores where the adjusted item scores are calculated by multiplying each behavior's frequency by its supportiveness. The range of scores for the individualized scales is 0 to 15. Higher scores on each of these domains reflect greater levels of perceived support.

In their original instrument validation study, Bearman and La Greca (2002) asked the friend support questions in a slightly different fashion. The response choices for the frequency questions was consistent with the current study, a five point Likert scale of "never (0), less than two times a month (1), twice a month (2), once a week (3), several times a week (4), or at least



once a day (5)," but the questions were posed as "How often does a friend...?" The supportiveness dimension of each question was asked "How does (would) this make you feel?" with a five point Likert scale response set, "not supportive (-1), neutral (0), a little supportive (1), supportive (2), and very supportive (3)." Using this scoring rubric, the psychometric properties of the instrument were adequate. Internal consistency as measured by Cronbach's alpha was .94; in the current study the alpha reliability was .90 indicating good internal consistency. Test-retest correlations were reported at least .78 and significant.

Bearman and La Greca found the DSSQ-Friends to demonstrate concurrent and discriminant validity. The individualized summary score was significantly correlated with diabetes-related support from friends ( $r^2=.49$ , p<.001) and general support from friends ( $r^2=.22$ , p<.05). The DSSQ-Friends correlated at a very low level with the diabetes-specific support from family ( $r^2=.35$ , p<.01) and general support from family ( $r^2=.22$ , p<.05) providing some support for discriminant validity. The individualized total scale did not demonstrate predictive validity as it did not predict illness management behaviors. The DSSQ-Friends has content and face validity (Hanna, 2006).

Diabetes Social Support Questionnaire-Parent (DSSQ-Parent). A measure of diabetesspecific social support for the caregivers of adolescents with diabetes was developed by the parent study research team as none existed in the literature at the time the study was initiated (Ellis, et al., 2006). The DSSQ-Parent was adapted from the DSSQ-Family and DSSQ-Friends; hence, the DSSQ-Parent assesses the same five areas of diabetes illness management as the family and friends instruments: insulin administration, blood glucose testing, meals, exercise, and emotional support. The DSSQ-Parent consists of 15 questions about support caregivers receive from "the person who help them the most with their teen's diabetes care". The questions



are the same as those asked on the DSSQ-Friends, but rephrased for caregivers to report on their support persons: 2 ask about insulin administration, 5 about blood glucose, 4 on exercise, and 3 tap emotional support. Caregivers are first asked to identify the adult who helps them the most with their adolescents' diabetes care. Thinking of this support person, questions are presented using the two-part Likert scale format described above. The first part of the question asks caregivers "How often does this person..." do each of the 14 supportive behaviors, to which caregivers respond "never (0), less than two times a month (1), twice a month (2), once a week (3), several times a week (4), or at least once a day (5)." The second part of each question asks the caregiver to rate the supportiveness, "How supportive (helpful) is this to you?", for each of the 14 behaviors using the 3-point Likert scale, "not at all, somewhat, or very".

The same scoring strategy used with the DSSQ-Family and DSSQ-Friends is used with the DSSQ-Parent. The total individualized summary score reflects the mean adjusted item scores, the frequency of each supportive behavior multiplied by the perceived supportiveness. The range of scores for the individualized scales is 0 to 15. Higher scores reflect greater levels of perceived support.

Given that this instrument is an investigator developed measure, formal psychometric testing has not been conducted. However, the instrument's reliability within the study sample is good at .91. There is also some evidence for discriminant validity as the DSSQ-Parent correlated at a low level with the diabetes-specific support from family ( $r^2$ =.24, p<.01) and support from the health care provider ( $r^2$ =.18, p<.05).

*Measure of Process of Care (MPOC-20).* Social support from the health care provider was assessed with the Measure of Process of Care-20 (MPOC-20; King, King, & Rosenbaum, 2004). This instrument is the abbreviated version of the full Measure of Process of Care (MPOC-



56; Susanne, Peter, & Gillian, 1996); both measures assess patients' perceptions of specific behaviors of health care professionals (King, et al., 2004). Two levels of support are assessed; health care provider support, that is, support from the health care professionals with whom patients interact during medical care visits, and support from the health care institution, that is, support from staff members of the health care institution as a whole which may include anyone from administrators to support persons such as receptionists and housekeeping staff.

Of the 20 items on the MPOC-20, 15 ask about support from health care providers and 5 query institutional support. The health care provider support questions ask caregivers "To what extent do the people who work with your teen..." provide the support described by each of the 15 items. The health care institution support questions ask "To what extent does the organization where you receive services..." provide the support described in each of the 5 questions. The response set for all items is a 7-point Likert scale, not at all (1), to a very small extent (2), to a small extent (3), to a moderate extent (4), to a fairly great extent (5), to a great extent (6), and to a very great extent (7), with the option for respondent to choose "does not apply (0)". A total summary scale was generated by calculating the mean response across all items. The range of possible scores is 1-7 where higher scores reflect greater levels of perceived support.

In their instrument development study, King, King, and Rosenbaum (2004) reported on the psychometric properties of the MPOC-20 by sub-scale. Internal consistency was satisfactory; the alphas ranged from .83 for the Providing Specific Information scale to .90 for the Providing General Information and Respectful and Supportive Care scales. In this study, alpha reliability was .94 indicating good internal consistency for the total summary scale. The five scales are intercorrelated (ranging from .56 to .87) indicating that the scales are measuring related but still distinct dimensions of a common construct. Construct validity was supported by the lack of



relationship between the MPOC-20 and patient demographic characteristics, including age, gender, community type, family structure, income, and education. Concurrent validity was established through positive correlation with a measure of treatment satisfaction and a negative correlation with a single-item measure of stress. The MPOC-20 has discriminant validity as determined by its ability to detect differences across different health care providers. The MPOC-20 has predictive validity as evidenced by its ability to predict perceptions of medical care, in a study of family-centered services.

**Diabetes Outcomes.** There are two primary diabetes outcomes: illness management behaviors and health status. In this study, both of these outcomes are measured objectively. Illness management behaviors are assessed by downloading adolescents' blood glucose meters. Metabolic control is the objective measure of diabetes health status.

*Illness Management Behaviors: Blood Glucose Meter (BGM).* To maintain optimal blood glucose levels, adolescents must test their blood glucose multiple times each day with a blood glucose meter. Each adolescent's blood glucose meter is downloaded to obtain objective data on blood glucose testing. Data obtained include the date, time, and blood glucose level for each blood glucose test performed. To compare blood glucose testing across participants, the average number of blood glucose tests per day performed over the 14-day period prior to the date of data collection is calculated. The primary limitation of using this data is that it measures only one aspect of diabetes illness management. The frequency of blood glucose testing is, however, very strongly associated with diabetes health (Anderson, et al., 1997).

*Diabetes Health Status: Metabolic Control.* Metabolic control is measured objectively via hemoglobin  $A_{1c}$  (Hb $A_{1c}$ ). Hb $A_{1c}$  is an indirect and retrospective measure of average blood glucose levels over the previous two to three month period. It is considered a valid and reliable



indicator of metabolic control and is extensively used for research purposes (M. M. Cohen, 1986). Adequate metabolic control is defined as having an  $HbA_{1c}$  maintained at or below 8.0% for youth 0-12 and at or below 7.5% for youth 12 and older (Silverstein, et al., 2005).

In the current study,  $HbA_{1c}$  is obtained at baseline using the Accubase  $A_{1c}$  test kit manufactured by Diabetes Technologies (Diabetes Technologies, 2004). The Accubase test is FDA approved and uses a capillary tube blood collection method instead of venipuncture. This collection technique makes it appropriate for home-based data collection by non-phlebotomists. Similar to venipuncture methods, high performance liquid chromatography (HPLC) is used to analyze the blood sample. Comparability of  $HbA_{1c}$  obtained by the Accubase test system to  $HbA_{1c}$  obtained from venous whole blood has been established in several studies, among sample of pediatric patients,  $R^2$ =.987 (Diabetes Technologies, 2004).

The target range for HbA<sub>1c</sub> values for children with diabetes aged 6 – 12 is  $\leq$ 8.0% while the target range is <7.5% for adolescents (13 to 19 years of age) with diabetes (Silverstein, et al., 2005). Higher HbA<sub>1c</sub> values indicate higher average levels of blood glucose which is indicative of poorer diabetes health status. Adolescents in this study had an average HbA<sub>1c</sub> of 11.7% (S.D = 2.55) reflecting very poor metabolic control.

Adolescent and Caregiver Demographics. Adolescent and caregiver demographic information was collected using an investigator-developed questionnaire (Ellis, et al., 2006). Caregivers provided information for both the adolescents and themselves via a structured interview. The caregiver was asked to answer first from their child and then for themselves. Adolescent and caregiver ages were calculated from their respective dates of birth. Adolescent and caregiver gender was queried with the male/female dichotomy. Adolescent and caregiver race was solicited using the following categories: Asian/Pacific Islander, American



Indian/Alaskan Native, Black/African American, Bi-racial, White/Caucasian, and Other, please specify. Adolescent and caregiver Hispanic/Latino heritage was captured separately as Yes or No. Adolescent and caregiver educational attainment was assessed by asking the highest level achieved using grades 1 through 12 (each was a selectable category), 1 to 11 years of college.

Caregivers were also asked to identify their relationship to the adolescent participant with the following categories: biological parent, legal guardian, step-parent, foster parent, adoptive Parent, and other, please specify. Caregivers present martial status was solicited as married to mother/father of this child, married but not to mother/father of this child, single or widowed, separated or divorced, single and living with a partner, or divorced and living with a partner. Caregivers were asked to identify the category of their family's yearly income from all sources: less than \$10,000; \$10,000 to \$19,999; \$20,000 to \$29,999; \$30,000 to \$39,999; \$40,000 to \$49,999; \$50,000 to \$59,999; \$60,000 to \$69,999; \$70,000 to \$79,999; \$80,000 to \$89,999; \$90,000 to \$99,999; \$100,000 or more; or don't know. Caregivers were asked if they were employed outside the home with Yes and No. And, finally, caregivers were asked to list all their dependents living in their home which were then tallied.

Adolescents' illness characteristics were obtained from a review of the medical chart. Duration of diabetes and age at time of diagnosis were calculated from the adolescent's date of diagnosis. Type of diabetes was recorded as Type 1 or Type 2. And, the prescribed illness management regimen was captured as Traditional Shots (2-3 mixed injections), Basal-Bolus Injections, or Insulin Infusion Pump.

#### **Data Analysis Plan**

The data analysis plan stems directly from the study aim, to test a social ecological model of social support for adolescents' diabetes care, and the study hypotheses. Figure 3 presents the





*Figure 3.* Theoretical model of social support for adolescents' illness management behavior and health status

empirical model for the study. Structural equation modeling (SEM) was chosen for this analysis. SEM is preferred over regression analyses due to the fact that it reduces the incidence of type 1 error by testing all structural relations simultaneously (Guo, Perron, & Gillespie, 2009). Structural equation modeling was conducted with Amos, PASW's structural equation modeling software (SPSS Inc., 2010a). The alpha level was set at .05 for all analyses.

The analysis was conducted following Kline (2005) and Arbuckle (2009). The structural equation model was evaluated in four stages. First, the fit of model to the data was assessed.



Three criteria were used to assess model fit: the chi-square statistic ( $\chi^2$ ), the comparative fit index (CFI), and the root mean square error of approximation (RMSEA). The  $\chi^2$  is a minimum sample discrepancy function that assesses the extent to which the sample covariances match the implied (i.e., population) covariances. Larger  $\chi^2$  values indicate greater differences between the sample and population; hence, nonsignificance is desired for good model fit. The  $\chi^2$  fit index is sensitive to sample size, both small and large; therefore, it is necessary to utilize additional indices to evaluate the model. The CFI compares the empirical model being tested with an alternative, baseline model, which is typically the independence model where all observed variables are uncorrelated. The CFI ranges from 0 to 1 where 1 suggests a perfect fit; thus, values closer to 1 represent better fit with the accepted rule of thumb being that any model falling below .9 is unacceptable. The RMSEA is another discrepancy function but is based on fitting the model using population estimates rather than sample estimates. RMSEA values less than or equal to .08 are considered adequate and values less than or equal to .05 are considered good fitting; a model with a RMSEA of .1 or higher would be rejected.

If the model demonstrated an adequate-good fit with the data, then next step was to evaluate the measurement model. The measurement model is the portion of the model that contains the latent construct for social support. The criteria for assessing the latent model was to first evaluate the factor loadings which are the regression weights associated with the paths pointing from the latent construct to each observed indicator variable. Factor loadings should be at least .3 which translates to a squared multiple correlation of .1 and be statistically significant. Factor loadings should also be roughly close in value to one another. If the model fits the data and the measurement model is adequate, the structural portion of the model can be evaluated.





*Figure 4.* Theoretical model of social support for adolescents' illness management behavior and health status

The structural portion of the model is the portion that describes the causal relationships between variables. SEM analyses generate both unstandardized and standardized results. Standardized estimates were analyzed as they are unaffected by the model identification process, for a full discussion see Arbuckle (2009, pp. 81-99). The regression weights assigned to the arrows pointing from one variable to another are interpreted in a fashion similar to multiple regression. In the text output file, each regression weight has a significance value that determines



whether that particular path is significant. These significance values were used to assess the structural component of the model and to trim nonsignificant paths from the model.

Finally, modification indices (MI) were used to determine which covariates would be included in the final model. MIs provide a conservative estimate of the change in  $X^2$  that would occur if a proposed modification is made. The threshold for covariates to be included into the model was maintained at the default level of 4. Since all model modifications are to be theoretically justified, changes to the model based on MIs were made only for the addition of covariates that were identified during the data screening phase.

To prepare the data for analysis, data screening guided by both Kline (2005) and Mertler and Vanetta (2005) was conducted. All data screening was conducted using the Predictive Analytics Software Statistics (PASW Statistics), version 18.0 (SPSS Inc., 2010b). The alpha level was set at .05 for all analyses. Univariate statistics were used to identify problems with individual variables, such as outliers, and to assess for violations of the normality assumption. Bivariate statistics were generated to assess for conformity to the linearity and homoscedasticity assumptions. In addition, the data was screened for conformity to the assumptions of multivariate analyses including multivariate linearity and multicollinearity.

Demographic characteristics of both adolescents and their caregivers were expected to impact their perceptions social support and adolescents' diabetes outcomes. Covariate relationships were specified using t-tests, analysis of variance, and Pearson's correlations during the data screening phase of the analysis.



## **CHAPTER 5 RESULTS**

This chapter will present the results of the statistical analysis. These results are presented in two sections. The first section describes the data screening performed prior to the initiation of the analyses. The second section presents the findings from the structural equation modeling (SEM) analyses.

## **Data Screening**

Data screening was conducted prior to the initiation of the SEM analyses to assess the data for conformity to distributional assumptions as outlined by Mertler & Vannatta (2005) unless otherwise indicated. First, the individual variables were examined to evaluate whether they were normally distributed. Next, linearity and homoscedasticity were evaluated. Third, multivariate linearity and potential for any multicollinearity of variables were assessed. Finally, the relationship between study variables and participant characteristics were examined to identify potential covariates.

**Normality Screening.** The distribution of each study variable was examined to assess conformity to the assumption of normality. This screening included examining the mean and standard deviation, minimum and maximum values, z-scores, the skewness and kurtosis coefficients, the Kolmogorov-Smirnov Test statistic, as well as histograms, stem and leaf, boxplots, and the normal probability plot of each individual variable. In addition, the Cronbach's alpha reliability coefficient was generated for each of the questionnaire-based measures. Table 3 summarizes the results of these analyses.

*Diabetes Social Support Questionnaire-Family Version (DSSQ-Family).* Five of the sixty-four items on the DSSQ-Family had one missing response which represented 0.7% of the data on these items and one item had two missing responses representing 1.4% of the data for



		Range						
Instrument*	Ν	М	SD	Potential	Actual	Skew	Kurtosis	Outliers
DSSQ-Family	146	4.35	2.20	0-15	0.16/9.50	.298	658	No
DSSQ-Friend	146	4.34	2.55	0-15	0.0/10.00	.067	787	No
DSSQ-Parent	145	3.48	3.13	0-15	0.0/10.00	.256	-1.259	No
MPOC-20	143	5.29	1.23	1-7	2.20/7.00	540	661	No
BGM	142	2.36	1.54		0.0/6.14	.277	727	No
HbA <sub>1c</sub>	146	11.67	2.53		7.2/19.5	.785	.341	Yes

Table 3Psychometric Properties of Study Variables

*Note.* DSSQ-Family = Diabetes Social Support Questionnaire-Family Version, DSSQ-Friend = Diabetes Social Support Questionnaire-Friend Version, DSSQ-Parent = Diabetes Social Support Questionnaire-Parent Version, MPOC = Measure of Processes of Care, BGM = Blood Glucose Meter,  $HbA_{1c}$  = Hemoglobin  $A_{1c}$ 

that item. These items were estimated using mean substitution prior to the computation of the summary scale. No respondent was missing the entire DSSQ-Family questionnaire. The mean score for respondents in this study was 4.35 (SD=2.20). Responses ranged from 0.16 to 9.50 in comparison to a potential range of 0-15. No outliers were identified when examining the z-scores (ranged from -1.90 to 2.34), the stem and leaf plot, and boxplot. An examination of the histogram suggested that the data had a slight negative skew; however, the normality assumption was supported by the skewness (.298) and kurtosis (-.658) coefficients as were both within the reference range of -1 to +1, as well as the results of the Kolmogorov-Smirnov Test being nonsignificant and the normal probability plot not deviating from the straight line.

*Diabetes Social Support Questionnaire-Friend Version (DSSQ-Friend).* None of the fifteen items on the DSSQ-Friend had missing responses and no respondent was missing the entire DSSQ-Friend questionnaire. The mean respondent score was 4.34 (SD=2.55) and responses ranged from 0.0 to 10.0 out of a potential range of 0-15. No outliers were identified when examining the z-scores (ranged from -1.70 to 2.22), the stem and leaf plot, and boxplot. An examination of the histogram suggested that the data were fairly normally distributed with slight platykurtosis. The skewness (.067) and kurtosis (-.787) coefficients supported this conclusion.



The Kolmogorov-Smirnov Test was nonsignificant. Finally, the normal probability plot did not deviate substantially from the straight line. Thus, the data can be assumed normally distributed.

Diabetes Social Support Questionnaire-Parent Version (DSSQ-Parent). Five of the thirty items on the DSSQ-Parent had one missing response which represented 0.7% of the data on these items. These items were estimated using mean substitution prior to computing the summary scales. One respondent was missing the entire DSSQ-Parent questionnaire; thus, the missing data on this questionnaire was 0.7%. Questionnaire level missing data was estimated using the expectation-maximization (EM) algorithm of the missing values analysis module of PASW. The mean score was 3.48 (SD=3.13). Responses ranged from 0.0-10.0 versus a potential range of 0-15. No outliers were found when examining the stem and leaf plot, the boxplot, and the z-scores (-1.11 to 2.08). An examination of the histogram determined that the data were bimodal. Roughly a third of the respondents (34.9%, N=51) had a score of 0 (no support) while the remaining participants' responses were normally distributed. A review of the data excluding those participants indicated that the mean score was 5.31 (SD=2.28). No outliers were found when the stem and leaf plot, the boxplot, and the z-scores (-2.33 to 2.06) were examined. An examination of the histogram indicated normality which was supported by the skewness (-.038) and kurtosis (-.556) coefficients, the results of the Kolmogorov-Smirnov Test (n.s.), and the normal probability plot.

*Measure of Processes of Care-20 (MPOC-20).* Seven of the twenty items on the MPOC-20 had one missing response which represented <1% of the data on these items. These items were estimated using mean substitution prior to computing the summary scales. Three respondents were missing the entire questionnaire; thus, the missing data on this questionnaire was 2.0%. Again, questionnaire level missing data was estimated using the Expectation-



maximization (EM) algorithm of the Missing Values Analysis module of PASW. Respondents' mean score was 5.29 (SD=1.23). A review of the standardized scores suggested that there were no outliers (ranged from -2.53 to 1.39) and the stem and leaf plot and boxplot both were consistent with this finding. A visual inspection of the histogram suggested that the data appeared to have a slight positive skew and platykurtosis. The skewness (-.540) and kurtosis (-.661) coefficients were within the range of acceptability and the normal probability plot deviated only slightly from the straight line. The result of the Kolmogorov-Smirnov Test, however, was significant (p<.001) which suggested a departure from the normality assumption.

**Blood Glucose Meter (BGM).** Four respondents were missing their BGM download; thus, the missing data on this measure was 2.7%. Missing data was estimated using the expectationmaximization (EM) algorithm of the missing values analysis module of PASW. Because BGM reflects the average number of tests per day over a two week period there is no maximum value, but there is a true 0 value. Participants in this study tested an average of 2.36 times per day (SD=1.54) with a range from 0 to 6.14 tests per day. A review of the standardized scores suggested that there were no outliers (ranged from -1.54 to 2.46); both the stem and leaf plot and boxplot were consistent with this result. A visual inspection of the histogram suggested that the data appeared to have some negative skew and some platykurtosis. The skewness (.277) and kurtosis (-.727) coefficients were, however, within the range of acceptability and the normal probability plot did not deviate from the straight line. The result of the Kolmogorov-Smirnov Test was marginally significant (p=.043) indicating a slight departure from the normality assumption.

*Hemoglobin*  $A_{Ic}$  (*HbA*<sub>Ic</sub>). No respondents were missing their HbA<sub>1c</sub> test results, as such, the missing data on this measure was 0%. There are no true minimum and maximum possible



values for the HbA<sub>1c</sub>; the mean was 11.67% (SD=2.53%) ranging from 7.2% to 19.5%. Although the stem and leaf plot and boxplot both suggested that there were three extreme values on the high end of the distribution, only one standardized score was outside the range of  $\pm 3$  standard deviations from the mean (3.09 which corresponded to the HbA<sub>1c</sub> value of 19.5%). Hence, there was one outlier. A visual inspection of the histogram suggested that the data appeared to have a slight positive skew; however, the skewness (.785) and kurtosis (.341) coefficients were within the range of acceptability. The result of the Kolmogorov-Smirnov Test, on the other hand, was significant (p=.001) and the normal probability plot deviated somewhat from the straight line, particularly at the extremes. These data suggested a departure from the normality assumption, which is expected for a laboratory value where the desired range is on the low end of the scale and, hence, fewer individuals would have high values.

Linearity and Homoscedasticity Sceening. An inspection of the scatterplot matrix that included all study variables was conducted. Several variable combinations demonstrated nonelliptical shapes which are indicative of a deviation from the normality and linearity assumptions. Thus, the scatterplots of standardized predicted and residual regression function values were examined.

Two regression models and scatterplots were generated since both BGM and HbA<sub>1c</sub> are conceptualized as outcome variables. In the first, BGM was entered as the dependent variable and in the second, HbA<sub>1c</sub>; the remaining study variables were entered as independent variables in both analyses. In both scatterplots, the shape of the plot did not demonstrate the extreme clustering indicative of non-normality, nonlinearity, or heteroscedasticity. There was however, a slight megaphone effect in the BGM scatterplot, suggesting that heteroscedasticity might play a role for larger values of BGM. Nonetheless, no egregious violations of the linearity assumption


were noted.

Multivariate linearity was assessed by examining the Mahalanobis distances generated when all continuous variables were entered as independent variables into a linear regression function. The critical Chi-square value at p<.001 and df=5 is 20.51. No cases exceeded this critical value and, hence, there are no multivariate outliers in the data.

**Multicollinearity Screening.** Multicollinearity was assessed by examining the tolerance and the variance inflation factors (VIF) from the regression analysis of all continuous variables described above. All diagnostics were within the acceptable range: tolerances were greater than 0.20 and VIFs were all less than 5. Thus, multicollinearity was not a concern with this data.

**Identification of Covariates.** Data screening included an assessment of the relationship between adolescents and their caregivers' demographics, adolescent illness characteristics and social support and outcome variables. The findings from these analyses are presented in Tables 4, 5, and 6. Table 4 presents the findings from the analysis of adolescent demographic characteristics and study variables. Adolescent race, age at study entry, and grade in school all demonstrated significant relationships with study variables.

Two of the four sources of social support were significantly related to adolescent demographic characteristics. Adolescent age and grade in school were related to adolescents' perceptions of diabetes-specific social support from family. Adolescent age was negatively related to diabetes-specific social support from family; in other words, as age increased support decreased ( $r^2 = -.358$ , p<.001). A similar trend was found for grade in school. Adolescents in high school (M = 3.58, SD = 1.98) reported the lowest levels of social support from their family. Their level of support was lower than their peers in elementary school (M = 4.65, SD = 2.16) and significantly lower than adolescents in middle school (M = 5.04, SD = 2.20), who reported the



	DSSQ-	DSSQ-	DSSQ-	MPOC-	DCM	
	Family	Friends	Parent	20	BGM	$HbA_{1c}$
Race or Ethnicity						
Levene's Test	1.932	1.737	0.224	4.617*	0.756	4.414*
<i>t</i> -test	-0.037	1.327	1.270	0.991	-3.682**	4.645**
African	$4.34 \pm$	$4.49 \pm$	$3.66 \pm$	$5.35 \pm$	$2.13 \pm$	$12.10 \pm$
American	2.11	2.48	3.16	1.29	1.50	2.54
Other Races	$4.36 \pm$	$3.82 \pm$	$2.87 \pm$	5.14 ±	$3.23 \pm$	$10.22 \pm$
	2.50	2.77	3.01	0.97	1.38	1.88
Gender						
Levene's Test	3.093	0.198	1.092	2.635	0.256	0.054
<i>t</i> -test	0.083	1.925	-1.202	-1.502	-0.491	1.333
Female	$4.36 \pm$	$4.69 \pm$	$3.21 \pm$	$5.16 \pm$	$2.31 \pm$	$11.92 \pm$
	2.34	2.59	3.00	1.27	1.57	2.58
Male	$4.33 \pm$	$3.88 \pm$	$3.84 \pm$	$5.47 \pm$	$2.44 \pm$	$11.36 \pm$
	2.03	2.45	3.29	1.15	1.51	2.45
Age	358**	074	212*	073	391**	.296**
Grade in School						
Levene's Test	0.738	0.194	0.054	0.836	0.645	5.525*
<i>t</i> -test	8.312**	0.232	2.115	0.351	7.358*	4.457*
Elementary	$4.65 \pm$	$4.71 \pm$	$4.54 \pm$	$5.48 \pm$	$3.58 \pm$	$10.21 \pm$
School: $4^{th}$ to $5^{th}$	2.16	2.60	3.37	1.23	1.50 <sup>a, b</sup>	1.19 <sup>a</sup>
grade						
Middle School:	$5.06 \pm$	$4.35 \pm$	$3.76 \pm$	$5.34 \pm$	$2.41 \pm$	$11.50 \pm$
6 <sup>th</sup> to 8 <sup>th</sup> grade	2.20 <sup>a</sup>	2.63	3.10	1.13	1.56 <sup>c</sup>	2.31
High School:	$3.58 \pm$	$4.23 \pm$	$2.96 \pm$	$5.22 \pm$	$2.01 \pm$	$12.20 \pm$
9 <sup>th</sup> and up	1.98 <sup>b</sup>	2.49	3.05	1.32	1.36 °	2.82 °

Table 4Bi-variate Relationship Between Social Support and Outcome Variables and AdolescentDemographic Variables

<sup>a</sup>denotes significant differences from adolescents in High School at p = .05 in Tukey post hoc analyses <sup>b</sup>denotes significant differences from adolescents in Middle School at p = .05 in Tukey post hoc analyses <sup>c</sup>denotes significant differences from adolescents in grades 1-5 at p = .05 in Tukey post hoc analyses \*p < .05\*\*p < .001

highest levels of support from family; F(2,143)=8.312, p<.001.

Similarly, caregivers' perceptions of social support from others were related to adolescent age. Caregivers of older adolescents reported lower levels of social support from others ( $r^2 = -.212$ , p=.010). Perceptions of social support from the health care provider did not vary with adolescent demographic characteristics; however, adolescents' diabetes outcomes did vary with their demographic characteristics.



Adolescents' illness management varied with adolescents' ethnicity, age, and grade in school. African American adolescents (M=2.13, SD=1.50) demonstrated lower levels of illness management compared to adolescents of other races (M=3.23, SD=1.38); t(140)=3.682, p<.001. Illness management was inversely related to adolescent age and grade in school. Illness management decreased as adolescent age increased ( $r^2 = -.391$ , p<.001). Adolescents in high school (M = 2.01, SD = 1.36) reported the lowest levels of illness management, followed by adolescents in middle school (M = 2.41, SD = 1.56) and adolescents in elementary school (M = 3.58, SD = 1.50). The difference between adolescents in high school and those in both middle school and elementary school were statistically significant; F(2,139)=7.358, p<.001.

Adolescent health status varied similarly. African American adolescents (M=12.10, SD=2.54) demonstrated poorer health (higher HbA<sub>1c</sub>) than adolescents of other races (M=10.22, SD=1.88); t(144)=4.645, p<.001. Adolescent age was positively related to health status such that older adolescents had higher HbA<sub>1c</sub>s which is indicative of poorer health. And, adolescents in high school (M = 12.20, SD = 2.82) demonstrated poorer health than their peers in both middle (M = 11.50, SD = 2.31) and elementary school (M = 10.21, SD = 1.19), F(2,143)=4.457, p=.013. The difference between adolescents in high and elementary school was statistically significant.

Table 5 presents the relationships between caregiver demographic variables and social support and diabetes outcome study variables. Caregiver race, gender, education, and family income all demonstrated significant relationships with study variables. Two of the four sources of social support were significantly related to caregiver demographic characteristics. Adolescent-reported diabetes-specific social support from family was related to caregivers' educational status. Adolescents reported the lowest levels of family support when their caregiver had less than a high school education (M = 3.52, SD = 1.46) as compared to caregiver with a



Table 5

Bi-variate Relationship Between Social Support and Outcome Variables and Caregiver Demographic Characteristics

Demographic Cha	DSSQ-	DSSQ-	DSSQ-	MPOC-20	BGM	HbA <sub>1c</sub>
	Family	Friends	Parent			
Relationship						
Levene's Test	0.001	1.053	0.338	0.786	0.467	0.714
t-test	-0.396	-0.219	0.517	-0.640	-0.101	-0.951
Biological	4.33 ±	4.32 ±	$3.52 \pm$	$5.28 \pm$	$2.36 \pm$	$11.62 \pm$
Parent	2.20	2.57	3.10	1.24	1.55	2.49
Other	4.61 ±	4.51 ±	$2.99 \pm$	$5.54 \pm$	2.41 ±	$12.41 \pm$
	2.27	2.40	3.68	1.01	1.40	3.08
Ethnicity						
Levene's Test	1.501	3.540	0.334	1.255	0.590	3.796
t-test	0.039	1.278	1.161	1.037	-4.257**	3.723**
African	$4.35 \pm$	$4.48 \pm$	$3.65 \pm$	5.36 ±	$2.09 \pm$	$12.09 \pm$
American	2.12	2.45	3.17	1.26	1.47	2.56
Other Races	$4.33 \pm$	$3.85 \pm$	$2.94 \pm$	5.11 ±	$3.33 \pm$	$10.32 \pm$
	2.46	2.85	2.99	1.11	1.37	1.92
Gender						
Levene's Test	2 270	0.544	0 620	0.033	2 225	0.001
t-test	-1 523	-1 902	-1 984*	0.971	0.260	0 753
Female	$4.26 \pm$	$421 \pm$	$332 \pm$	$5.33 \pm$	$2.38 \pm$	$11.72 \pm$
	2.16	2.56	3.32 = 3.10	1 23	1.50 =	2 55
Male	5 23 +	5.61 +	5.10	4 97 +	2 26 +	11.17 +
White	2.51	$2.01 \pm 2.11$	$3.11 \pm 3.11$	1.97 -	$2.20 \pm 2.00$	2.38
Δσε	027	081	- 040	- 024	- 034	- 006
Grade	.027	.001	.010	.021	.051	.000
Levene's Test	3 847*	1 851	1 377	0.203	3 505*	1 539
t_test	3 243*	1.051	0.167	2 179	1 385	2 033
I ess Than	3 52 +	3.59 +	3.73 +	5 27 +	2 86 +	12.033
High School	$5.52 \pm 1.46^{a}$	$3.37 \pm 2.04$	$3.75 \pm 2.04$	$3.27 \pm 1.34$	$2.00 \pm$	$12.14 \pm 2.48$
High School	1.40	2.0 <del>4</del> 1.58 +	2.94	5 57 +	$2.10 \pm$	12.40
or Equivalent	$7.05 \pm 2.00^{b}$	$+.50 \pm$ 2.50	3 38	1.18	$2.17 \pm 1.72$	$12.03 \pm 2.75$
Greater Than	2.20	$2.39 \pm 1.39 \pm$	3.50	$5.11 \pm$	1.72 2.36 +	$\frac{2.73}{11.24}$
High School	$+.23 \pm$	$+.39 \pm$	$3.34 \pm$	$3.11 \pm 1.20$	$2.30 \pm$	$11.24 \pm 22$
Morital Status	2.32	2.00	5.04	1.20	1.50	2.33
I avana's Test	0.020	0.250	0.636	2 6 2 2	0.054	0.750
t tost	0.920	0.230	1.014	0.299	1 250	0.730
l-lest Single Derent	-0.000	0.197	-1.914	-0.200	-1.230	1.347
Single Patent	$4.24 \pm$	$4.37 \pm 2.56$	$3.07 \pm 2.10$	$3.27 \pm 1.21$	$2.23 \pm 1.46$	$11.94 \pm 2.64$
Tree Demonte	2.10	2.30	5.10	1.31	1.40	2.04
I wo Parents	$4.50 \pm$	$4.29 \pm 2.56$	$4.07 \pm$	$5.34 \pm$	$2.56 \pm$	$11.29 \pm$
	2.35	2.56	3.12	1.11	1.63	2.33
Employment	0.000	0.000	0.040	0.250	4 550*	0.015
Levene's Test	0.899	0.006	0.248	0.359	4.552*	0.015
<i>t</i> -test	1.109	1.493	-0.460	1.323	-1.109	1.204
Do Not Work	$4.60 \pm$	$4.73 \pm$	$3.33 \pm$	$5.47 \pm$	$2.19 \pm$	$11.99 \pm$
Outside the	2.33	2.56	3.25	1.27	1.62	2.41
Home	4.4.0	1.00	2.50		• • •	
Works Outside	$4.18 \pm$	$4.08 \pm$	$3.58 \pm$	$5.19 \pm$	$2.48 \pm$	$11.47 \pm$



	DSSQ-	DSSQ-	DSSQ-	MPOC-20	BGM	$HbA_{1c}$
	Family	Friends	Parent			
the Home	2.11	2.53	3.07	1.19	1.48	2.60
Income						
Levene's Test	3.875	0.869	1.781	0.120	0.084	2.513
<i>t</i> -test	-0.051	0.422	-0.507	1.412	-3.124*	3.190*
\$29,999 or	$4.34 \pm$	$4.43 \pm$	$3.34 \pm$	$5.45 \pm$	$1.96 \pm$	$12.34 \pm$
Less	1.95	2.45	3.27	1.21	1.47	2.62
\$30,000 or	4.35 ±	4.25 ±	3.61 ±	5.16 ±	$2.74 \pm$	$11.04 \pm$
More	2.43	2.66	3.01	1.23	1.51	2.29
# Dependents	.075	.137	.045	046	.042	.018

<sup>a</sup>denotes significant differences from caregivers with a high school education at p = .05 in Tukey post hoc analyses

<sup>b</sup>denotes significant differences from caregiver with less than a high school education at p = .05 in Tukey post hoc analyses

\**p*<.05

\*\**p*<.001

high school education (M = 4.85, SD = 2.20) or greater than a high school education (M = 4.23, SD = 2.32); F(2,143)=3.243, p=.042. The difference between caregivers with less than a high school education and those with a high school education was statistically significant in Tukey post hoc testing.

The other significant difference in social support related to caregiver gender. Male caregivers (M = 5.11, SD = 3.11) reported significantly higher levels of social support from others than their female counterparts (M = 3.32, SD = 3.10); t(143)=1.984, p=.049. Adolescents' perceptions of social support from their friends and caregiver's perceptions of support from the health care provider did not vary with caregiver demographic characteristics.

Adolescents' diabetes outcomes did vary with caregiver ethnicity and family income. The adolescents of African American caregivers (M=2.09, SD=1.47) demonstrated lower levels of illness management compared to other race caregivers (M=3.33, SD=1.37); t(144)=4.257, p<.001. Likewise, adolescents with African American caregivers (M=12.09, SD=2.56) demonstrated poorer health (higher HbA<sub>1c</sub>) than adolescents with caregivers of other races (M=10.32, SD=1.92); t(144)=3.723, p<.001. This finding is unsurprising since adolescents and



caregivers share their ethnic heritage.

Family income was also related to adolescent illness outcomes. Because income was collected using a categorical variable, the data were divided into two groups using a median split. The lower income group included the roughly half of the participants (48.6%, N = 71) who reported annual incomes less than \$30,000 per year, while the higher income group include the 51.4% (N = 75) of the participants who reported annual incomes of \$30,000 a year or more. Adolescents living in low income families had poorer levels of illness management and poorer health. Specifically, adolescents in families reporting an annual income of \$30,000 or less (M = 1.96, SD = 1.47) had lower levels of blood glucose monitoring than families with incomes of \$30,000 or more (M = 2.74, SD = 1.51); t(140)=3.124, p=.002. This difference was replicated for adolescent health status. Adolescents in families with incomes less than \$30,000 (M = 12.34, SD = 2.62) had higher HbA<sub>1c</sub> levels, which indicate poorer health, than families reporting an annual income of \$30,000 or more (M = 11.04, SD = 2.29); t(144)=3.190, p=.002.

Table 6 presents the relationship between adolescent illness characteristics and social support and diabetes outcome variables. Age at diagnosis, type of diabetes, and insulin delivery regimen were significantly related to study variables. Two sources of social support were significantly related to diabetes illness characteristics. Adolescent age at diagnosis was related to adolescents' perceptions of social support from family. Adolescents diagnosed with diabetes at older ages reported lower levels of support from their family ( $r^2 = -.165$ , p=.047). Friend support varied by the type of insulin regimen the adolescent was prescribed; F(3,143)=2.916, p=.036. Adolescents prescribed basal only regimens reported the highest levels of friend support (M = 6.44, SD = 2.44), whereas adolescents on insulin infusion pump regimens report the lowest levels of support from friends (M = 3.16, SD = 2.41). The difference between these two groups



	DSSQ- Family	DSSQ- Friends	DSSQ- Parent	MPOC- 20	BGM	$HbA_{1c}$
Age at diagnosis	165*	.070	138	071	354**	.263**
Duration of illness	064	139	.011	.041	.146	107
Diabetes Type						
Levene's Test	0.156	0.408	0.009	0.024	2.653	1.175
<i>t</i> -test	-0.331	-1.969	1.740	-0.695	4.344**	-1.779
Type 1	$4.32 \pm$	$4.19 \pm$	$3.65 \pm$	$5.27 \pm$	$2.56 \pm$	$11.54 \pm$
51	2.19	2.50	3.09	1.21	1.48	2.45
Type 2	4.51 ±	$5.47 \pm$	$2.25 \pm$	$5.49 \pm$	$0.94 \pm$	$12.69 \pm$
	2.35	2.72	3.29	1.38	1.18	2.97
Prescribed Insulin						
Regimen						
Levene's Test	2.250	0.105	3.877*	2.245	1.114	2.589
ANOVA	1.657	2.341	1.619	1.234	7.985**	2.628
Conventional	4.19 ±	$4.19 \pm$	$2.86 \pm$	5.31 ±	$1.76 \pm$	$12.01 \pm$
Mixed Injections	2.05	2.56	2.58	1.36	1.27 <sup>a, b</sup>	2.80
Basal-Bolus	$4.50 \pm$	4.51 ±	$3.82 \pm$	5.21 ±	$2.58 \pm$	$11.86 \pm$
Injections	2.32	2.50	3.31	1.25	1.53 <sup>c, d</sup>	2.47
Insulin Infusion	$3.49 \pm$	$3.24 \pm$	$3.82 \pm$	$5.42 \pm$	$3.28 \pm$	$9.93 \pm$
Pump	1.67	2.36	3.45	0.84	1.41 <sup>c, d</sup>	1.57
Basal Injection	$6.30 \pm$	$6.80 \pm$	$1.69 \pm$	6.19 ±	$0.44 \pm$	$12.58 \pm$
Only	2.20	2.55	2.31	0.50	$0.88^{a, b}$	2.00

 Table 6
 Bi-variate Relationship Between Study Variables and Disease Characteristics

<sup>a</sup>denotes significant differences from adolescents on basal-bolus injection regimens at p = .05 in Tukey post hoc analyses

<sup>b</sup>denotes significant differences from adolescents on insulin infusion pump regimens at p = .05 in Tukey post hoc analyses

<sup>c</sup>denotes significant differences from adolescents on conventional mixed injection regimens at p = .05 in Tukey post hoc analyses

<sup>d</sup>denotes significant differences from adolescents on basal only regimens at p = .05 in Tukey post hoc analyses

\**p*<.05 \*\**p*<.001

of adolescents was statistically significant. Adolescents prescribed conventional mixed injection regimens (M = 4.19, SD = 2.56) and those on basal-bolus injection regimens (M = 4.51, SD = 2.50) reported intermediate levels of friend support. Neither support for the adolescents' caregivers nor support from the health care provider were related to illness characteristics.

Adolescent illness outcomes also varied by illness characteristics. Age at diagnosis was inversely related to both illness management and health status. Adolescent diagnosed at older ages performed fewer blood glucose tests than their peers diagnosed at younger ages ( $r^2 = -.354$ ,



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p < .001). adolescent health status was positively related to age at diagnosis indicating that youth diagnosed at older ages had higher HbA<sub>1c</sub>s, suggesting poorer diabetes-related health status ( $r^2 =$ .263, p<.001). Illness management also varied by diabetes type. Adolescents with type 1 diabetes (M = 2.56, SD = 1.48) performed more blood glucose tests each day than those with type 2 (M = 0.94, SD = 1.18); t(140)=4.344, p<.001. Finally, adolescents who received their insulin via an intensive insulin regimen, either a basal-bolus injection regimen (M = 2.58, SD = 1.53) or an insulin infusion pump (M = 3.28, SD = 1.41), had significantly higher levels of daily blood glucose monitoring than those youth on either conventional mixed insulin injections (M = 1.76, SD = 1.27) or those on basal insulin only regimens (M = 0.44, SD = 0.88); F(3,139)=8.422, p < .001. Similarly, adolescents prescribed insulin via an infusion pump (M = 9.87, SD = 1.60) were in the best diabetes health with an HbA<sub>1c</sub> significantly lower than adolescents prescribed conventional mixed insulin injections (M = 12.07, SD = 2.80) and those on basal-bolus injection regimens (M = 11.86, SD = 2.47); F(3,143)=3.777, p=.012. Adolescents on basal insulin only regimens (M = 12.32, SD = 1.91) were in the worst health, but this difference was not statistically significant.

These analyses identified several possible covariates of study variables: adolescent age, grade, and ethnicity; caregiver gender, race, and education; and adolescent age at diagnosis, type of diabetes, and insulin regimen. To improve the parsimony of the statistical model several secondary analyses were undertaken to reduce the number of covariates added to the model.

First, Pearson's correlations between adolescents' age at study entry, grade, and age of diagnosis were generated. These age indicators were all positively correlated at  $r^2$ =.513 or greater and statistically significant at the *p*<.001 level, see Table 7. Hence, is only one of these indicators was included in the statistical model.



Table 7Correlations Among Age Indicators

	Age at Study Entry	Grade in School
Grade in School	.868**	
Age at Diagnosis **p<.001	.594**	.513**

Second, the relationship between adolescent and caregiver ethnicity was examined. A chi-square analysis of the relationship between these two variables, presented in Table 8, indicates that they too were significantly related to one another,  $\chi^2=129.525$ , p<.001 level. Adolescents shared their primary caregivers' ethnic heritage 97.9% (143) of the time; therefore,

only adolescent ethnicity was included in the final model.

Retationship Detween A	aolescent and Cureg	iver Einnichy		
		Caregiver	_	
		African		
		American	Other Races	Total
Adolescent Ethnicity	African American	98.2% (111)	1.8% (2)	100% (113)
	Other Races	3.0% (1)	97.0% (32)	100% (33)
Total		76.7% (112)	23.3% (34)	100% (146)
Chi-square = 129.525*	**			
**p<.001				

Table 8Relationship Between Adolescent and Caregiver Ethnicity

A chi-square analysis was also conducted to examine the relationship between adolescent race and family income. Table 9 presents the results of this analysis. African American adolescents fell disproportionately into the lower income category in comparison to their other race peers,  $\chi^2$ =7.785, *p*=.005. Thus, controlling for adolescent ethnicity also controlled for income related differences.



		Family I		
		\$29,999 or	\$30,000 or	
		less	more	Total
Adolescent Ethnicity	African American	54.9% (62)	45.1% (51)	100% (113)
	Other Races	27.3% (9)	72.7% (24)	100% (33)
Total		48.6% (71)	51.4% (75)	100% (146)
Chi-square = 7.785**				
**p<.01				

Table 9Relationship Between Adolescent Ethnicity and Family Income

Finally, a chi-square analysis was conducted to explore the relationship between type of diabetes and insulin delivery regimen. Table 10 presents the results of this analysis. The distribution of adolescents prescribed conventional mixed injection and basal-bolus injection regimens were slightly greater among adolescents with type 1 diabetes (27.9%, N=36 and 57.4%, N=74) versus those with type 2 diabetes (23.5%, N=4 and 47.1%, N=8). The greatest difference was for adolescents prescribed insulin via infusion pump and those prescribed basal insulin only; no adolescents with type 2 diabetes were prescribed insulin via an infusion pump and no adolescents with type 1 diabetes were prescribed basal insulin only. These differences were statistically significant,  $\chi^2$ =40.834, *p*<.001. It is important to note that this is an expected finding; it would be unusual for anyone with type 2 diabetes to be prescribed insulin via an infusion pump and essentially impossible for anyone with type diabetes to be prescribed basal insulin only. Both of these variables were included as covariates in the statistical modeling.

#### **Structural Equation Modeling**

Structural equation modeling was utilized to evaluate the theoretical model. The theoretical model consists of two components, a measurement model and a structural model. The measurement model consists of the latent social support construct as indicated by the four unique



	_	Type of D	iabetes	
		Type 1	Type 2	Total
Insulin Delivery	Conventional	27.9% (36)	23.5% (4)	27.4% (40)
Regimen	Mixed Injections			
	Basal-Bolus	57.4% (74)	47.1% (8)	56.2% (82)
	Injections			
	Insulin Infusion	14.7% (19)	(0)	13.0% (19)
	Pump			
	Basal Only	(0)	29.4% (5)	3.4% (5)
Total		100% (129)	100% (17)	100% (146)
Chi-square = 40.834**				
**p<.001				

Table 10Relationship Between Type of Diabetes and Insulin Delivery Regimen

social ecological systems of social support for adolescents' illness management behavior. The structural model describes the relationship between social support and diabetes outcomes: social support is hypothesized to directly effect adolescent illness management behavior and indirectly effect adolescent health status (mediated effect).

**Theoretical Model.** Figure 4 displays the results of the analysis of the theoretical model. Although the fit indices indicated that the fit of the model was good ( $\chi^2$ =10.448; df=9; p=.315; CFI=.984; RMSEA=.033), the factor loadings on the latent construct did not support the hypothesis of one latent construct for social support. In order to support such a conclusion, the paths between the latent construct and each indicator should have a standardized regression weight greater than or equal to .3 and be statistically significant. Figure 4 clearly demonstrates this is not the case. Social support from family and social support from friends loaded onto the social support construct, but social support for the caregiver (.26, p=.022) and social support from the health care provider (.19, p=.071) did not. Further, this constellation of indicators explained 0% of the variance in social support. Interpretation of the structural component of the





*Figure 5.* Theoretical model of social support for adolescents' illness management behavior and health status (standardized regression weights)

model does not make sense given the failure of the measurement component of the model. An alterative model of social support was constructed based upon the findings from the theoretical model.

Alternative Model. The failure of the theoretical model can be understood from the perspective of social ecological theory. According to social ecological theory the most influential



interactions shaping an individual's behavior are those that occur within the context of his or her daily life. Thus, the social support influences shaping an adolescent's diabetes care behaviors are likely to be those interactions that adolescents have with their family and friends. Interactions with the health care provider and caregivers' interactions with their own support persons are, in comparison, more distal to the adolescent's daily diabetes care behavior. As such, the latent construct in the alternative model, Figure 5, was revised to represent social support from the adolescents' microsystem: support from family and support from friends. Given their more distal nature, social support from the adolescents' exosystem (support for the caregiver) and mesosytem (support from the health care provider) were hypothesized to impact adolescents' illness management behavior. Likewise, microsystem support as well as to affect adolescents' illness management behavior. Microsystem support was hypothesized to have an indirect effect (mediated effect) on adolescents' health status through its impact on illness management behavior.

Figure 6 presents the results from the analysis of this revised model. The fit of the revised model was good ( $\chi^2$ =11.241; df=7; p=.128; CFI=.952; RMSEA=.065). The factor loadings on the latent construct were supportive of the hypothesis that the two sources of social support (support from family and friends) were measuring an underlying microsystem social support construct. Specifically, the path between the latent social support construct and social support from friends was significant (.52, p=.027). Six percent (6%) of the variance in microsystem support from family and support fami





*Figure 6.* Alternative theoretical model of social support for adolescents' illness management behavior and health status

As for the structural components of the model, the path between exosystem support (support for the caregiver from others) and microsystem support was significant (.22, p=.006) suggesting that exosystem support provided to the caregiver is positively related to microsystem support. In other words, caregivers who perceive greater levels of support from others have adolescents who report greater levels of support from family and friends. Mesosystem support (from the health care provider) was not significantly related to microsystem support (.12, p=.119). Thus, the hypothesis that exo- and mesosytem support would be positively related to







microsystem support was only partially supported by the data.

None of the social support systems were significantly related to illness management: microsystem support (.18, p=.128), exosystem support (.09, p=.306), and mesosystem support (-.03, p=.685). As such, the hypothesis that micro-, exo-, and mesosystem support would independently contribute to adolescent illness management was not supported by the data.



Adolescents' illness management behavior was significantly related to adolescent health status (-.42, p<.001). As illness management increased, health status, as measured by adolescents' metabolic control, decreased; this is the desired relationship as lower levels of metabolic control are indicative of better health. Finally, the mediated effect of social support on health status was tested. The indirect effects of social support on health from each of the social support systems were nonsignificant when assessed using Sobel's test (Kline, 2005): microsystem support (-.087, p>.1), mesosystem support (.029, p>.1), and exosystem support (-.029, p>.1).

To improve the parsimony of the revised model, the nonsignificant paths, with the exception of the path between microsystem social support and illness management behavior were trimmed. Because mesosystem social support was not significantly related to either microsystem support or illness management behavior, it dropped out of the model. The trimmed model was re-estimated. Figure 7 presents the results from the analysis of this trimmed and revised theoretical model. The fit of the trimmed and revised model remained good ( $\chi^2$ =6.200; df=5; p=.287; CFI=.986; RMSEA=.041). The measurement portion of the model was unchanged (as expected) from the previous model.

Examining the structural portion of the model, the path between exosystem support (support for the caregiver from others) and microsystem support was slightly changed (.24, p=.003 versus .22, p=.006) in the more parsimonious model. An improvement in the relationship between microsystem support and adolescent illness management was noted. This relationship now approached significance, .20, p=.085. The relationship between adolescent illness management remained and adolescent health status was unchanged (-.42, p<.001). The mediated effect of microsystem support on health status in the revised and trimmed model remained nonsignificant (-.096, p>.1).





*Figure 8.* Trimmed, revised theoretical model of social support for adolescents' illness management behavior and health status (standardized regression weights)

A final model assessing the relationship between the covariates identified during the data screening analyses and the trimmed, revised model was estimated. First, all the covariates identified during the data screening phase were added to the model and the modification indices were used to guide the addition of covariances. Modification indices suggested that adolescent age, adolescent ethnicity, caregiver education, and type of diabetes were important covariates to be controlled for in the model; whereas caregiver gender and insulin delivery regimen did not



present a significant impact on the model. The final model is presented in Figure 8.

The fit of the resulting model was good, ( $\chi^2$ =19.991; df=16; p=.221; CFI=.977; RMSEA=.041). The addition of covariates slightly changed the measurement portion of the model. Specifically, the factor loading for social support for the adolescent from family was slightly reduced from .99 to .92 after controlling for adolescent age, while the factor loading for social support for the adolescent from friends was slightly increased from .52 to .56 after controlling for type of diabetes.

In the structural portion of the model, the path between exosystem support (social support for the caregiver) and microsystem support was also improved by the addition of adolescent age as a covariate (.26, p=.002 versus .24, p=.003). With the addition of adolescent age, adolescent ethnicity, and type of diabetes as covariates, the relationship between microsystem support and adolescent illness management was now significant (.22, p=.034). Five percent (5%) of the variance in illness management was explained by social support. The relationship between adolescent illness management and adolescent health status was relatively unchanged (-.43, p<.001 versus -.42, p<.001) with the addition of adolescent ethnicity and caregiver education as covariates. The mediated effect of microsystem support on health status was also now significant. Microsystem support was negatively related to health status through illness management behavior (-.122, p<.05). In other words, adolescents reporting higher levels of microsystem support had lower levels of metabolic control, which are indicative of better health, through the mechanism of higher levels of illness management behavior.





*Figure 9.* Final model of social support for adolescents' illness management behavior and health status (standardized regression weights)



## **CHAPTER 6 DISCUSSION**

In this chapter the findings of the research study will be discussed and connected to the existing state of knowledge. In addition, the potential limitations of the study as well as future directions for research will be identified. Finally, the implications of the work for the field of social work will be explored.

### A Social Ecological Model of Social Support for Adolescents with Diabetes

This study proposed a novel approach to examining social support for adolescents with diabetes. Research to date has focused primarily on how two sources of social support, support from adolescents' family and/or friends, impact adolescents' diabetes outcomes. Support from family and friends are the most logical sources of support to impact daily diabetes care behaviors as these are the individuals with whom adolescents interact on a daily basis. There are, however, other individuals within adolescents' social ecology that might contribute to their illness management. This study takes a broader look at the social ecology of adolescents with diabetes to include sources of social support more distal to the adolescents, yet still potentially influential in adolescents' daily diabetes care behavior: social support for the caregivers of adolescents with diabetes and support from adolescents' health care providers. Hence, the aim of this study was to examine a social ecological model of social support for adolescents with diabetes that includes social support for adolescents from family and friends, support for the adolescents' caregivers, and support for met health care provider.

**Theoretical Model.** In the theoretical model of social support for adolescents with diabetes proposed for the study, it was hypothesized that each of the four sources of social support independently contributed to an overall construct of social support. The data did not support this construction of social support for adolescents with diabetes. The factor loadings on



the latent social support construct suggested that the two proximal sources of social support, support to the adolescent from family and friends, were tapping an independent construct of social support. The more distal sources of social support, support for the caregiver and support from the health care provider, were not significantly associated with the more proximal sources of support. The failure of the measurement portion of the model (the latent social support construct) precluded any interpretation of the relationship between a global construct of social support and diabetes outcomes. Thus, study hypothesis 1, that each of the four sources of social support would independently and positively contribute to illness management when evaluated simultaneously was not supported. Hypothesis 2, that illness management behaviors would mediate the relationship between social support and adolescents' health status, could not be assessed with the theoretical model.

Social ecological theory explains the failure of the theoretical model. In proposition one Bronfenbrenner describes the most influential interactions in one's social environment as those reciprocal interactions that occur regularly within an individual's immediate environment and over an extended period of time (Bronfenbrenner, 2008). These interactions comprise the individual's microsystem influences and most typically involve interactions with family and friends. Hence, it makes theoretical sense that the two sources of social support assessing support for diabetes illness management behavior at the microsystem level would be most strongly related to one another. Social support for the caregiver and from the health care provider likely occur less frequently and, as such, would be related to microsystem support but would not tap the same latent construct that sources of microsystem support tap. Given these findings, an alternative model of social support was conceptualized.



An Alternative Model. In the alternative model of social support for adolescents' diabetes care, it was hypothesized that social support for the adolescent from family and from friends assesses the individuals' microsystem support for diabetes care. As more distal sources of social support, support for the caregiver and support from the health care provider were hypothesized to positively impact microsystem support but to differ from the more direct support adolescents receive from their family and friends. Therefore, caregivers who report higher levels of support from others and from the health care provider might be more likely to provide support to their adolescent children. Higher levels of micro-, meso-, and exosystem support were then hypothesized to directly impact adolescents' behavior (illness management) and indirectly impact adolescents' health.

The findings from the data analysis partially confirmed this revised model of social support. Social support from the health care provider was unrelated to either microsystem support or adolescent illness management behavior. Consequently, this variable was dropped from the model. The resulting model suggested that social support for the caregiver was positively related to adolescents' microsystem support. Microsystem support, in turn, was positively related to adolescents' illness management behavior. Adolescents' illness management behavior was negatively associated with adolescents' health status. In other words, caregivers who reported high levels of social support from their family and friends. Higher levels of social support from family and friends were associated with higher levels of illness management behavior and lower metabolic control, which is indicative of better health.

The revised model of social support provided some evidence for the study hypotheses. Hypothesis 1, that overall social support would be related to illness management behavior, was



not supported. Although microsystem support, as indicated by social support for the adolescent from family and friends, was related to adolescent's illness management behavior. Social support for the caregiver was only indirectly, through microsystem support, related to illness management. And, social support from the health care provider was unrelated to illness management. As discussed above, this finding is consistent with the assumptions of social ecological theory: regular, proximal interactions are those most likely to shape behavior. Hypothesis 2 proposed that illness management behaviors would mediate the relationship between social support and adolescents' health status. This hypothesis was supported by the data. Microsystem support was positively related to adolescent illness management behavior which, in turn, was negatively associated with adolescents' health status.

This study contributes to the literature by linking social support for the caregiver to adolescents' illness outcomes through adolescents' perceptions of social support. The existing research on social support for the caregivers of children with diabetes and other chronic illnesses has primarily focused on the correlates of social support (Florian & Krulik, 1991; Reiter-Purtill, et al., 2008) or the caregiver's own outcomes (Fuemmeler, et al., 2003; Reiter-Purtill, et al., 2008; Sullivan-Bolyai, et al., 2010). Few studies have examined the relationship between social support for the caregiver and children's outcomes. This may be due, in part, to the fact that more distal sources of social support, such as support for the caregiver, may not be directly related to children's illness outcomes but are rather indirectly related to illness outcomes through more proximal processes, such as enhancing the social support available to adolescents within their microsystem.

One study examining social support for caregivers of adolescents with diabetes did identify a link to illness management behavior (Lewandowski & Drotar, 2007). A close



examination of the methodology, however, reveals an interesting limitation. In this study, spousal support for mothers was related to nurse reports of illness management via the Health Care Provider Rating Questionnaire (HCPRQ), but the frequency of blood glucose monitoring (BGM), the objective measure of illness management used in this study, was not related to spousal support. Although the HCPRQ and BGM were correlated at .45, p<.01, the HCPRQ instrument may not be the best measure of illness management as it is a subjective measure based mainly on adolescent and family self-report of illness care during clinical interactions; hence, it is a third-hand report of illness management behavior. A model of social support similar to the one examined in this study, where social support for the caregiver is indirectly related to illness management behavior, may have found a significant relationship between the social support system and the objective measure of illness management behavior.

An unexpected finding was the fact that social support from the health care provider was unrelated to microsystem support and adolescent illness management behavior and, hence, dropped out of the model. There are several reasons that this may have occurred. First, social ecological theory suggests that support from the health care provider may be too infrequent and distal an interaction to have a significant impact on adolescents' daily illness management behavior. This is a plausible explanation given the fact that the adolescent participants in this sample are very high risk, as indicated by their very poor health and living in primarily lowincome, single parent households. Such youth are more likely than other populations of adolescents with diabetes to miss their regularly scheduled clinic appointments (Karter, et al., 2004; Thompson, Auslander, & White, 2001a) and, as a consequence, may feel less connected to their health care provider. Although the data suggested respondents had positive perceptions of



the social support they receive from their health care providers, the infrequency of interaction may have been a critical component.

A second consideration is the fact that social support from the health care provider was assessed by the caregivers alone. It is possible that the adolescents' perspective on social support from the health care provider might be more strongly related to adolescent illness management behavior. Or, a combination of reports from both the caregiver and the adolescent might paint a more accurate portrait of mesosystem support. Perhaps from the caregiver's perspective the health care provider is being very supportive and helpful, but the adolescent does not agree.

Finally, the lack of a relationship between social support from the health care provider and other study variables might be related to the instrument itself. The Measure of Processes of Care-20 (MPOC-20) asks caregivers to assess the overall social support they receive from a variety of health care providers they interact with for their adolescents' diabetes care. This includes the doctors, nurses, dietitians, medical assistants, and medical students, as well as any other hospital clinical and support staff they have interacted with during the course of their care. Overall feelings of support from the health care team and the institution as a whole may be more strongly related to attendance at clinic than to daily illness management behavior. Health care provider support that is related to daily diabetes illness management behavior and/or adolescents' microsystem support may be located within specific relationships. For example, an adolescent may be more likely to feel supported by the nurse who he/she calls weekly to report blood glucose readings. Similarly, caregivers might be more likely to identify the dietician who helped them to problem-solve meal planning for their family that includes children both with and without diabetes as a source of health care provider support. A measure of health care provider support that first identifies an important support person within the health care team might better



capture social support from the health care provider. Or, perhaps, an assessment of each member of the health care team might identify the salient source of support located with this mesosystem.

# The Relationship Between Social Support and Adolescent, Caregiver, and Illness Characteristics.

In addition to the findings related to the testing of the theoretical model, this study identified additional important relationships between the different sources of social support and respondent characteristics.

Adolescent Perceptions of Social Support from Family. Similar to other studies of diabetes-specific social support from family, older adolescents in this study reported lower levels of social support from their families than younger adolescents (Hanson, et al., 1987; La Greca & Bearman, 2002). Youth in middle school reported the highest levels of support from their families and high school students reported the lowest levels of support. Where other studies have suggested a more linear decrease in the support relationship (Hanson, et al., 1987; La Greca & Bearman, 2002), this study suggests there may be a period of time when support temporarily increases, and then decreases. This finding suggests that parents might recognize the difficulty in transitioning to independent illness management and temporarily increase their level of support. Longitudinal studies on social support would better clarify whether these differences reflect actual changes in degree of support over time or merely reflect within sample-variability.

A second finding was related to caregiver education. The adolescents of caregivers with less than a high school education reported lower levels of support than adolescents whose caregivers had a high school education or greater. One other study examined the relationship between caregiver education and adolescent perceptions of social support, but this study found the two to be unrelated (Hsin, et al., 2009). This finding suggests that among high risk



adolescents in poor diabetes health, having a parent with less than a high school education may present a risk for lower levels of support from family members. Reasons for this finding are unclear and could have many explanations. For instance, parents with less education may earn less money and, hence, may be forced to work more hours or juggle several jobs, reducing their availability to provide support to adolescents.

Adolescent Perceptions of Social Support from Friends. Unlike other studies of social support for diabetes from friends (Helgeson, Lopez, et al., 2009; La Greca, et al., 1995; Shroff Pendley, et al., 2002; Skinner & Hampson, 1998; Skinner, et al., 2000), adolescents in this study did not report age and gender differences in their perceptions of social support for their diabetes from friends. Explanations for why this group of adolescents differed from other populations of adolescents are unclear. It might be that the youth in this study have not disclosed their illness to their peers. A lack of disclosure seriously undermines or eliminates the ability of friends to provide support to adolescents living with diabetes (La Greca, et al., 2002). Another possible explanation may be that the high risk youth in this study might discourage or rebuff friend support for diabetes care in an effort to minimize any differences between themselves and their peers. Further research is needed to understand friend support in populations of high risk youth with diabetes.

**Caregivers Perceptions of Social Support from Others.** The caregivers in this study reported an age-related trend similar to that found for adolescents' perceptions of family support. Caregivers reported decreasing perceptions of social support from others as the age of their adolescents increased. This finding is interesting given the relationship between increasing age, decreasing social support for the adolescent from family, and decreasing illness management and



diabetes health. Perhaps a parallel phenomenon is occurring at the parental level such that others have a perception that as adolescents increase in age they are more responsible and their caregivers are, hence, less in need of social support for their adolescents' illness management.

Caregivers in this study reported gender differences in their perceptions of social support. Male caregivers reported much higher levels of social support for their adolescents' diabetes than their female peers. There is little research published on male caregivers as the majority of studies have focused on mothers, the traditional caregivers (e.g., Florian & Krulik, 1991; Fuemmeler, et al., 2003; Lewandowski & Drotar, 2007). Of the studies that have been conducted that examined gender differences, the focus has been on the types or sources of social support identified as helpful (Patterson, et al., 1997) or comparisons of the caregivers of chronically ill children with caregivers of healthy children (Reiter-Purtill, et al., 2008) rather than on the differential experience of support. The ability of male caregivers to recognize a variety of behaviors or individuals as supportive may help to explain the discrepancy found in this study. To illustrate, Patterson, et. al (1997) found that fathers identified informational support provided from service providers to be more supportive in comparison to female caregivers. Another explanation of the discrepancy might be that male caregivers receive more assistance from others in times of need, highlighting a gender bias in our society. Male caregivers may be seen as less accustomed to being responsible for their children's day-to-day care, including their health care; thus, individuals in their support network may be more likely to step up and assist with the adolescents' diabetes illness management.

**Caregiver Perceptions of Social Support from the Health Care Provider.** Perceptions of health care provider support did not vary based upon adolescent, caregiver, or illness characteristics. This may be due to the very high ratings of health care provider support. As little



is known about the impact of social support from the health care provider, additional research is needed to explore this issue.

#### **Study Limitations**

Sample. Youth enrolled in this study were targeted because of their poor illness management behavior and poor health status. They were primarily African American youth living in low-income, single-parent, urban homes. These characteristics may limit the generalizability of the study's findings to the broader population of youth with diabetes. Replication with diverse samples is needed to confirm the study's findings.

Although the sample size was adequate for SEM, for which the sample size should be between 100 and 200 (Kline, 2005), a larger sample may have had greater power to detect hypothesized relationships. Specifically, the relationship between health care provider support and other study variables may have been enhanced with a larger sample size.

Cross-sectional data. This study is limited by the use of a cross-sectional data set. Causal relationships are difficult to determine with cross-sectional data due to the fact that a sequence of behavior can not be determined without specific planning for doing so. Thus, the directionality of the relationship between social support and the diabetes outcomes is informed by theory but cannot be confirmed using methodology such as that in the current study.

Instruments. The range of responses on the social support measures was restricted in comparison to the available range of responses. To illustrate, each of the Diabetes Social Support Questionnaires has a potential range of responses from 0 to 15, but the actual responses were limited to 0.16 to 9.50 for the DSSQ-Family and 0 to 10 for both the DSSQ-Friend and DSSQ-Caregiver. Furthermore, the mean response on these questionnaires averaged around 3.5 to 4.3 with a relatively small standard deviation. Such limited variability on the DSSQ instruments may



have contributed to the low percentage of variance in social support explained in the SEM analysis.

While the Diabetes Social Support Questionnaires are empirically supported diabetesspecific measures of social support; the Measure of Process of Care (MPOC) is not. The MPOC does assess supportive aspects of health care provider-patient relationships (King, et al., 2004), however, a significant relationship may have been found if a diabetes-specific measure of health care provider support had been used. Future research is needed to develop such a measure.

The use of a single reporter for each sub-system within families' social ecologies also limits the data to that individual's perspective. As family systems are complex and dynamic, the inclusion of multiple reporters from each sub-system is recommended (Kazak, 1997). Getting both adolescent and caregiver perspectives on each of the social support variables might have strengthened the observed relationships between variables and increased the percent of variance explained. On the other hand, it makes sense that caregivers would report on their own perceptions of social support and adolescents' on their own perspectives.

#### **Future Research**

This study represents the first to examine a model of social support where distal sources of social support are hypothesized to impact more proximal sources of support and through this mechanism, impact illness management behavior in chronically ill adolescents. As such, further research is needed to confirm this theoretical model. Perhaps with broader samples and larger sample sizes, a link between the more distal sources of social support and illness management behavior could be identified.

In addition to examining the theoretical model, further research examining social support from the health care provider is also needed. Several hypotheses were presented that may



warrant further investigation. First, further research is needed to understand if, indeed, health care provider support is too infrequent and distal an interaction to have a significant impact on adolescents' daily illness management behavior. Research with more representative samples of adolescents with diabetes, versus very high risk adolescents in poor health, is needed. Second, the adolescents' perspective on health care provider support is needed as their perspective may be related to illness outcomes. Finally, the instrumentation used to assess social support from the health care provider needs to be examined to identify the most relevant clinicians and clinician behaviors for supporting adolescents' daily illness management behavior.

Two age-related findings suggest further examination. A pattern of temporarily heightened support from family for youth in middle school was identified in this research. Research is needed to understand this pattern. Do parents recognize the difficulty their children face in transitioning to autonomous care and, consequently, increase their support? Or, is there some other explanation for this pattern of temporarily increased support leading to deterioration over time. A similar age-related decrease in social support for caregivers was found. Such decreases may be related at a systemic level. Caregivers who experience less support from others may decrease their own support of the adolescent in response to this social cue that their child is now old enough to care for his/her diabetes independently or they may experience an increase in their own stress or other responses that compromise their ability to provide support to their adolescent. Such insight has clinical as well as empirical significance.

Another potential avenue for research arising out of this study is understanding why high risk youth, like those who participated in this study, may not have the same gender differences in friend support as has been reported for other populations of youth with and without diabetes. Are female youth in this study, because of their poor illness management and poor health, less likely



to disclose their illness to their peers and, therefore, less likely to have friend support available to them? Further research is needed to understand this difference.

Research is also needed to understand the gender difference in support for the caregiver. It is not clear why the male caregivers in this study reported much higher levels of social support for their adolescents' diabetes than their female peers. Is soliciting social support a skill that can be learned or is there a more pervasive social phenomenon occurring? Further research is needed to understand the reasons male caregivers report greater perceptions of social support for their adolescents' diabetes care.

In a field dominated by medicine, nursing, and psychology, more research from a social work perspective is needed. Several study findings fit well with the social work tradition and, hence, social work researchers would be positioned well to explore these issues.

#### **Social Work Implications**

Adolescents living with diabetes must adhere to a rigorous and demanding self-care regimen. Divergence from this illness management routine has dire consequences for adolescents' short- and long-term health. Given the complexities of this regimen and the seriousness of breakdowns in illness management, medical care providers are primarily focused on these illness management behaviors, often overlooking other factors that may contribute to difficulty with illness management. Social work has a tradition of examining problems from a family perspective, trying to understand how the individual's problems relate to and are sustained by the family system as a whole. This research provides empirical evidence for this holistic view of the adolescent with diabetes. The findings from this study suggest that social support can benefit illness management through dynamic family processes as well as have a direct impact on behavior. As such, it provides additional evidence for targeting the caregivers of



adolescents with diabetes for medical social work intervention: bolstering the social support of caregivers may help to improve adolescent illness management.

In his seminal writings on social support over thirty years ago, Stanley Cobb identified teaching patients how to give and receive social support to be an excellent fit within the field of medical social work (Cobb, 1976). The call to include social workers on multidisciplinary treatment teams persists today (Delamater, 2007). Medical social workers, as members of multidisciplinary diabetes treatment teams, can advance a more complete picture of the adolescent with diabetes by promoting a more comprehensive view of the psychosocial factors, such as social support, impacting adolescents living with diabetes, and extending treatment beyond the individual to include the family (Thompson, et al., 2001b). With a more complete understanding of the adolescent and his social ecology, medical social workers can further advocate for the preservation of adolescents' and their families' autonomy and foster a sense of mastery over their illness (Thompson, et al., 2001b).

In addition to identifying another source of social support for adolescents' illness management, this research also identifies specific risk factors that social workers could use to tailor their assessment and intervention. The temporary increase in family support during middle school identified in this population of high risk youth suggests a critical point for intervention. Supporting the caregivers of adolescents with diabetes during middle and into high school may help to assuage the age-related decreases in social support from family and offset the deterioration in illness management behavior and health as youth move toward adulthood. Also, age-related differences in social support for caregivers as well. The literature has established a link between decreased social support for adolescents and poorer illness management behavior, and



now this study offers some evidence for a similar relationship for support for the caregiver. This evidence provides medical social workers with another piece of evidence for bolstering support for caregivers of adolescents with diabetes.

In addition to the known age and contextual vulnerabilities some adolescents face, this study brings to light additional risk factors that social workers in a medical setting might wish to attend to. Specifically, adolescents of caregivers with lower levels of education (less than a high school education) may be at risk for lower levels of family support. Social workers working with such youth may find it especially informative and useful to assess the social support provided to the adolescent from family and the need for intervention.

Finally, the population of adolescents who participated in this study has been largely neglected by previous researchers and is underserved by the medical community. Eliciting these adolescents' perspectives and making their voices heard promotes a more comprehensive and responsive medical care system. It is the mission of social work to advocate for the disenfranchised or otherwise overlooked and excluded populations of our society.



## APPENDIX A IRB CONCURRANCE OF EXEMPTION



HUMAN INVESTIGATION COMMITTEE 101 East Alexandrine Building Detroit, Michigan 48201 Phone: (313) 577-1628 FAX: (313) 993-7122 http://hic.wayne.edu



#### CONCURRENCE OF EXEMPTION

To:	April Carcone Pediatrics Pediatric Preve	ntion Research
From:	Ellen Barton, Pl Chairperson, B	h.D ehavioral Institutional Review Board (B3)
Date:	February 15, 20	010
RE:	HIC #:	023010B3X
	Protocol Title:	A Social Ecological Perspective on Diabetes Care: Supporting Adolescents and Cargivers
	Sponsor:	
	Protocol #:	1002008043

The above-referenced protocol has been reviewed and found to qualify for Exemption according to paragraph #4 of the Department of Health and Human Services Code of Federal Regulations [45 CFR 46.101(b)].

· Waiver of consent has been requested and approved.

This proposal has not been evaluated for scientific merit, except to weight the risk to the human subjects in relation to the potential benefits.

- · Exempt protocols do not require annual review by the IRB.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC BEFORE implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (http://www.hic.wayne.edu/hicpol.html).

#### NOTE:

- 1. Forms should be downloaded from the HIC website at each use.
- 2. Submit a Closure Form to the HIC Office upon completion of the study.



# **APPENDIX B INSTRUMENTS**

# DIABETES SOCIAL SUPPORT QUESTIONNAIRE - FAMILY

Please think not just about your \_\_\_\_\_\_, but about everyone who lives in your house who might help you with your diabetes care. This questionnaire asks about different things that your family could do to support you, or help you, with your diabetes care. Each question has two parts. The first part asks **how often** your family helps you with your diabetes; you can choose never, less than 2 times a month, twice a month, once a week, several times a week or at least once a day. The second part of each question asks **how much** of a help this is for you; please decide if this not at all helpful, somewhat helpful or very helpful. Please be sure to answer both parts of each question.

S. Help you with your homework?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	(1) t at all (0)	Some (.	ewhat 1)	V	<sup>7</sup> ery (2)
1. Give you your insulin?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	V	/ery (2)
2. Remind you to take your insulin?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	Very (2)	
3. Praise you for giving yourself insulin correctly or on time?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	V	/ery (2)
4. Help out when you give yourself insulin?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not at all (0)		Some	ewhat 1)	V	/ery (2)
5. Wake you up so you can take your morning insulin on time?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)

## How often does your family:


How supportive (helpful) is this	Not at all		Some	ewhat	Very		
to you?		0)	(1	)	(	(2)	
6. Change their own schedule to		Less than	Twice a	Once a	Several	At least	
get an early start, when you	Never	2 times a	month	week	times a	once a day	
give yourself morning	(0)	month	(2)	(3)	week	(5)	
insulin?	(1)		(-) (0)		(4)	(5)	
How supportive (helpful) is this	Not	Not at all Somewhat V		V	ery		
to you?		0)	(1	)		(2)	
7. Check after you've taken		Less than	Twice a	Once a	Several	At least	
your insulin to make sure you	Never	2 times a	month	week	times a	once a day	
have done it?	(0)	month	(2)	(3)	week	(5)	
		(1)	(-)	(5)	(4)	(5)	
How supportive (helpful) is this	Not at all		Some	what	V	ery	
to you?		0)	(1	)	(	(2)	
8. Let you know they		Less than	Twice a	Once a	Several	At least	
understand how difficult it is	Never	2 times a	month	week	times a	once a day	
to take insulin?	(0)	month	(2)	(3)	week	(5)	
		(1)	(-)	(5)	(4)	(0)	
How supportive (helpful) is this	Not	at all	Some	ewhat	V	ery	
to you?		0)	(1	)		(2)	
		Less than	Twice a	Once a	Several	At least	
9. Ask you about the results of	Never	2 times a	month	week	times a	once a day	
your blood tests?	(0)	month	(2)	(3)	week	(5)	
_		(1)	(2)	(3)	(4)	(3)	
How supportive (helpful) is this	Not	at all	Some	ewhat	V	ery	
to you?	(0)		(1	)	(2)		
10 Watch you test your blood		Less than	Twice a	Once a	Several	At least	
sugars to see what the values	Never	2 times a	month	week	times a	once a day	
are?	(0)	month	(2)	(3)	week	(5)	
uic:		(1)	(2)	(5)	(4)	(5)	
How supportive (helpful) is this	Not	at all	Somewhat		V	ery	
to you?		0)	(1)		(	(2)	
		Less than	Twice a	Once a	Several	At least	
11. Test your blood sugar for	Never	2 times a	month	week	times a	once a day	
you?	(0)	month	(2)	(3)	week	(5)	
		(1)	(-)	(5)	(4)	(0)	
How supportive (helpful) is this	Not	at all	Somewhat		Very		
to you?	(	(0)	(1	)	(	(2)	
12. Remind you to test your	N	Less than	Twice a	Once a	Several	At least	
blood sugars to see what the	Never	2 times a	month	week	times a	once a day	
values are?	(0)	month	(2)	(3)	week	(5)	
		(1)		1	(4)		
How supportive (neipful) is this	INO	at all	Some	ewnat	V	ery	
to you?	(	U) Logg them	(1	)	<u> </u>	2)	
12 Males auro you have motorials	Novor	Less than	Twice a	Once a	Several	At least	
15. Wake sure you have materials	(O)	2  times a	month	week	times a	once a day	
needed for blood testing?	(0)	montn (1)	(2)	(3)	week	(5)	
Users and actives (hale ful) is this	Nat	(1)	Como		(4)		
How supportive (neipful) is this	INO	at all	Some	ewnat	V	ery	
		U) Logg them	()	)	<u> </u>	(2)	
14. Let you know that they	Nover	2 times a	Twice a	Once a	several	At least	
understand how hard it is to	INPVEE	$\angle$ nmes a			umes a	anaa a dari	
		manth	month	week	···· a a 1-	once a day	
test blood sugars every day?	(0)	month	month (2)	(3)	week	(5)	
test blood sugars every day?	(0)	month (1)	(2)	(3)	week (4)	(5)	



to you?	(	(0)	(1	1)	(2)		
15. Set up materials you need for testing you blood sugar?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all (0)	Some	Somewhat (1)		Very (2)	
16. Praise you for testing your blood sugar on your own?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this	Not	at all (0)	Some	ewhat 1)	V	(2)	
17. Help out when you test your blood sugar?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	V	(2)	
18. Keep track of testing results for you?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not at all (0)		Somewhat (1)		Very (2)		
19. Watch for signs that your blood sugar is low?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all	Somewhat (1)		Very (2)		
20. Help out when you might be having a reaction?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	Very (2)		
21. Suggest ways you can get exercise?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat l)	V	(2)	
22. Remind you to exercise?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	V	(2)	
23. Invite you to join in exercising with them?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	(1) Not at all (0)		Somewhat (1)		Very (2)		



		Less than	Twice a	Once a	Several	At least		
24. Congratulate or praise you for exercising regularly?	Never (0)	2 times a month	month (2)	week	times a week	once a day		
How supportive (helpful) is this	Not	(1)	Some	ewhat	(4) V	(4) Very		
to you?		(0) Loss then	()	l)	Coveral (	(2)		
25. Encourage you to join an organized sports activity?	Never (0)	2 times a month	Twice a month (2)	Once a week (3)	times a week	At least once a day (5)		
How supportive (helpful) is this to you?	Not at all (0)		Some	ewhat 1)	V	(2)		
26. Buy sports equipment for you?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	Not at all		ewhat	V	/ery (2)		
27. Exercise with you?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not at all (0)		Somewhat (1)		Very (2)			
28. Are available to listen to concerns or worries about your diabetes care?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	at all	Somewhat (1)		V	Very (2)		
29. Give you things to read on diabetes care?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	at all	Somewhat (1)		Very (2)			
30. Tell you how well you've been doing with your diabetes care?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	V	(2)		
31. Encourage you to do a good job of taking care of your diabetes?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this	Not	at all (0)	Some(1	ewhat	V	(2)		
32. Understand when you sometimes make mistakes in taking care of your diabetes?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat	Very (2)			



## **DIABETES SOCIAL SUPPORT QUESTIONNAIRE - FRIENDS**

Please think about your friends. This questionnaire asks about different things that your friends could do to support you, or help you, with your diabetes care. Each question has two parts. The first part asks **how often** your friends helps you with your diabetes; you can choose never, less than 2 times a month, twice a month, once a week, several times a week or at least once a day. The second part of each question asks **how much** of a help this is for you; please decide if this not at all helpful, somewhat helpful or very helpful. Please be sure to answer both parts of each question.

### How often do your friends...

U							
<ol> <li>Remind you to take your insulin?</li> <li>How supportive (helpful) is this</li> </ol>	$\begin{array}{c} & \text{Less tha} \\ \text{ur} & \text{Never} & 2 \text{ times} \\ (0) & \text{month} \\ \hline \\ \text{) is this} & \text{Not at all} \end{array}$		Twice a Once a month week (2) (3) Somewhat		Several times a week (4)	At least once a day (5)	
to vou?	(	(0)	(1	D	(	(2)	
<ol> <li>Let you know how important it is to take insulin?</li> </ol>	Never (0)	Less than Never 2 times a (0) month (1)		Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this	Not	t at all	Some	ewhat	V	ery	
to you?		(0)	(1	1)		(2)	
3. Ask you about the results of your blood tests?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not at all (0)		Some	ewhat l)	Very (2)		
4. Remind you to test your blood sugar?	Never (0)	Less than Never 2 times a (0) month (1)		Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	t at all (0)	Somewhat (1)		Very (2)		
5. Let you know that they understand how important it is to test blood sugar?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	t at all (0)	Some (1	ewhat l)	V	ery 2)	
6. Watch you for signs that your blood sugar is low?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat	Very (2)		
7. Help out when you might be having a reaction?	Never (0)	Less than 2 times a	Twice a month	Once a week	Several times a	At least once a day	



		month	(2)	(3)	week	(5)
How supportive (helpful) is this	Not	(1) at all	Some	ewhat	(4) V	erv
to you?	(	(0)	()	1)	. (	(2)
8. Suggest ways you can get exercise?	Never (0)	Less than 2 times a month	Twice a month (2)	Once a week (3)	Several times a week	At least once a day (5)
How supportive (helpful) is this to you?	Not	at all	Some	Somewhat		ery (2)
<ol> <li>Invite you to join in exercising with them?</li> </ol>	Never (0)	Less than Never 2 times a (0) month (1)		Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	V (	ery 2)
10.Encourage you to join an organized sports activity?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not at all (0)		Some	ewhat 1)	V (	ery (2)
11.Exercise with you?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)
How supportive (helpful) is this to you?	Not	at all (0)	Some	ewhat 1)	V (	ery (2)
12.Available to listen to concerns or worries about	Never	Less than 2 times a	Twice a	Once a week	Several times a	At least
your diabetes care?	(0)	month (1)	month (2)	(3)	week (4)	(5)
your diabetes care? How supportive (helpful) is this to you?	(0) 	$\begin{array}{r} \text{month} \\ (1) \\ \hline \text{at all} \\ (0) \end{array}$	month (2) Some	(3) ewhat 1)	(4) (4) (4)	(5) (5)
your diabetes care? How supportive (helpful) is this to you? 13.Encourage you to do a good job of taking care of your diabetes?	(0) Not Never (0)	month (1) at all (0) Less than 2 times a month (1)	Twice a month (2) Twice a month (2)	(3) ewhat 1) Once a week (3)	week (4) V Several times a week (4)	(5) (ery 2) At least once a day (5)
your diabetes care? How supportive (helpful) is this to you? 13.Encourage you to do a good job of taking care of your diabetes? How supportive (helpful) is this to you?	(0) Not Never (0) Not	month (1) (at all (0) Less than 2 times a month (1) (0)	month (2) Some (1) Twice a month (2) Some (1)	(3) ewhat 1) Once a week (3) ewhat 1)	week (4) V ( Several times a week (4) V (	(5) fery 2) At least once a day (5) fery 2)
your diabetes care? How supportive (helpful) is this to you? 13.Encourage you to do a good job of taking care of your diabetes? How supportive (helpful) is this to you? 14.Understand when you sometimes make mistakes in taking care of your diabetes?	(0) Not (0) Not (0) Never (0)	month (1) at all (0) Less than 2 times a month (1) at all (0) Less than 2 times a month (1)	month (2) Some (1) Twice a month (2) Some (1) Twice a month (2)	(3) ewhat 1) Once a week (3) ewhat 1) Once a week (3)	week (4) V Several times a week (4) V Several times a week (4)	(5) ery 2) At least once a day (5) ery 2) At least once a day (5)
your diabetes care? How supportive (helpful) is this to you? 13.Encourage you to do a good job of taking care of your diabetes? How supportive (helpful) is this to you? 14.Understand when you sometimes make mistakes in taking care of your diabetes? How supportive (helpful) is this to you?	(0) Not Never (0) Not (0) Not	$\begin{array}{r} \text{month} \\ (1) \\ \hline (1) \hline \hline (1) \\ \hline (1) \hline \hline (1) \\ \hline \hline (1) \hline \hline (1) \\ \hline \hline $	month (2) Some (1) Twice a month (2) Twice a month (2) Some (1)	(3) ewhat 1) Once a week (3) ewhat 1) Once a week (3) ewhat 1)	week (4) V Several times a week (4) V Several times a week (4) V	(5) ery 2) At least once a day (5) ery 2) At least once a day (5) ery 2) Conce a day (5) ery 2) Conce a day (5) Conce a day (5) (5) (5) (5) (5) (5) (5) (5)
your diabetes care?         How supportive (helpful) is this to you?         13.Encourage you to do a good job of taking care of your diabetes?         How supportive (helpful) is this to you?         14.Understand when you sometimes make mistakes in taking care of your diabetes?         How supportive (helpful) is this to you?         15.How many of your friends know you have diabetes?	(0) Not Never (0) Not None (0)	month (1) (at all (0) (1) (1) (1) (2) (2) (2) (2) (2) (3) (2) (3) (3) (3) (4) (4) (5) (4) (5) (5) (5) (1) (1) (5) (1) (1) (1) (1) (1) (1) (1) (1) (1) (1	month (2) Some (1) Twice a month (2) Some (1) Some friends (2)	(3) ewhat 1) Once a week (3) ewhat 1) Once a week (3) ewhat 1) Most/All (3)	week (4) V Several times a week (4) V Several times a week (4) V	(5) ery 2) At least once a day (5) ery 2) At least once a day (5) ery 2) Conce a day (5) ery 2) Conce a day (5) ery 2) Conce a day (5) Conce a day (5) (5) (5) (5) (5) (5) (5) (5)



# **DIABETES SOCIAL SUPPORT QUESTIONNAIRE - PARENT**

*This next questionnaire asks about the person who helps you the most with your \_\_\_\_\_'s diabetes care.* 

First, who is the person who helps you the most with your teen's diabetes care?

Is this person a family member?	Yes (1) / No (0)
Does this person live in your home?	Yes (1) / No (0)

Now, each question has two parts. The first part asks how often this person helps you with your \_\_\_\_\_\_''s diabetes care; you can select never, less than 2 times a month, twice a month, once a week, several times a week or at least once a day. The second part of each question asks how much of a help this is for you; please decide if this not at all helpful, somewhat helpful or very helpful. Please be sure to answer both parts of each question.

### How often does this person ...

S. Help your teen with his/her homework?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this	How supportive (helpful) is this Not at all		Some	what	Very		
to you?	(	$\frac{0}{1}$	(1	!)	(	2)	
1. Remind your teen to take his/her insulin?	Never (0)	2 times a month (1)	Twice a month (2)	Once a week (3)	times a week (4)	At least once a day (5)	
How supportive (helpful) is this	Not at all		Some	ewhat	V	ery	
to you?	(	<u>()</u>	()	)	(	2)	
2. Let your teen know how important it is to take insulin?	Never (0)	2 times a month (1)	Twice a month (2)	Once a week (3)	times a week (4)	At least once a day (5)	
How supportive (helpful) is this	Not	at all	Somewhat		V	ery	
to you?	(	(0)	(1)		(2)		
3. Ask your teen about the results of his/her blood tests?	Less than Never 2 times a (0) month (1)		Twice a monthOnce a week(2)(3)		Several times a week (4)	At least once a day (5)	
How supportive (helpful) is this	Not	at all	Some	ewhat	V	ery	
4. Remind your teen to test	Never	Less than 2 times a	Twice a	Once a week	Several times a	At least once a day	
his/her blood sugar?	(0)	month (1)	(2)	(3)	week (4)	(5)	
his/her blood sugar? How supportive (helpful) is this to vou?	(0)	month (1) at all (0)	(2) Some	(3)	(4)	(5) ery 2)	



he/she understands how important it is to test blood sugar?	(0) 2 times a month (1)		month (2)	week (3)	times a week (4)	once a day (5)		
How supportive (helpful) is this	Not	t at all (0)	Some	ewhat 1)	V	Very (2)		
6. Watch your teen for signs that his/her blood sugar is low?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Twice a monthOnce a week(2)(3)		At least once a day (5)		
How supportive (helpful) is this to you?	Not	Not at all (0)		ewhat l)	V (	(2)		
7. Help your teen out when he/she might be having a reaction?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	V	(2)		
8. Suggest to your teen ways he/she can get exercise?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	Not at all		ewhat 1)	V	(2)		
9. Invite your teen to join in exercising with him/her?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	Very (2)			
10.Encourage your teen to join an organized sports activity?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	t at all (0)	Somewhat (1)		Very (2)			
11.Exercise with your teen?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this	Not	t at all (0)	Some	ewhat 1)	V	(ery (2)		
12.Available to listen to your teen's concerns or worries about diabetes care?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to you?	Not	t at all (0)	Some	ewhat 1)	V	(2)		
13.Encourage your teen to do a good job of taking care of his/her diabetes?	Never (0)	Less than 2 times a month (1)	Twice a month (2)	Once a week (3)	Several times a week (4)	At least once a day (5)		
How supportive (helpful) is this to vou?	Not	(1) t at all (0)	Some	ewhat 1)	Very (2)			
14.Understand when your teen sometimes make mistakes in	Never (0)	Less than 2 times a	Twice a month	Once a week	Several times a	At least once a day		



taking care of his/her diabetes?		month (1)	(2) (3)	week (5) (4)
How supportive (hel	pful) is this to you?	Not at all (0)	Somewhat (1)	Very (2)
15.How many of your friends know your teen has diabetes?	None (0)	Only my best friend(s) (1)	Some friends (2)	Most/All (3)
How supportive (hel	pful) is this	Not at all	Somewhat	Very
	to you?	(0)	(1)	(2)



# **MEASURE OF PROCESSES OF CARE - 20**

We would like to understand and measure the experiences of parents and teens who are working to improve their teen's diabetes care. In particular, we wish to know about <u>your</u> perceptions of the care you have been receiving <u>over the past 6 months</u> from the health care organization that provides services to your teen. This refers to your experiences at Children's Hospital of Michigan and how your treatment is going there.

The care that you and your teen receive from this organization may bring you into contact with many individuals. The questions on this form are grouped by <u>who</u> these contacts are, as described below.

**PEOPLE**: refers to those individuals who work <u>directly</u> with you or your teen. These **may** include psychologists, therapists, social workers, doctors, nurses, dieticians, etc.

**ORGANIZATION**: refers to <u>all staff</u> from Children's Hospital of Michigan, whether involved directly with your teen or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The questions are based on what parents, like yourself, have told us about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate <u>how much</u> the event or situation happens to you. You are asked to respond by circling **one** number from 1 (Not at All) to 7 (To a Very Great Extent) that you feel best fits your experience. Please note that the zero value (0) is used only if the situation described does not apply to you.

Indicate how much	this event	or situation	happens	to you.
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IN THE PAST 6 MONTHS, TO WHAT EXTENT DO THE <b>PEOPLE</b> WHO WORK WITH YOUR TEEN	To a Very Great Exte nt	To a Great Exte nt	To a Fairl y Great Exte nt	To a Mod erate Exte nt	To a Smal 1 Exte nt	To a Very Smal l Exte nt	Not at All	Does Not Appl y
S offer you a snack in clinic?	7	6	5	4	3	2	1	0



IN THE PAST 6 MONTHS, TO WHAT EXTENT DO THE <b>PEOPLE</b> WHO WORK WITH YOUR TEEN	To a Very Great Exte nt	To a Great Exte nt	To a Fairl y Great Exte nt	To a Mod erate Exte nt	To a Smal 1 Exte nt	To a Very Smal l Exte nt	Not at All	Does Not Appl y
1help you to feel competent as a parent?	7	6	5	4	3	2	1	0
2provide you with written information about your child's treatment?	7	6	5	4	3	2	1	0
3provide a caring atmosphere <u>rather</u> than just give you information?	7	6	5	4	3	2	1	0
4let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
5look at the needs of your child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
6make sure that at least one clinic staff is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
7fully explain treatment choices to you?	7	6	5	4	3	2	1	0
8provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
9provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
10plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
11treat you as an <u>equal</u> rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
12give you information about your teen that is consistent from person to person?	7	6	5	4	3	2	1	0
13treat you as an individual rather than as a "typical" parent of a child with diabetes?	7	6	5	4	3	2	1	0
14provide you with written information about your teen's progress?	7	6	5	4	3	2	1	0
15tell you about the results from tests?	7	6	5	4	3	2	1	0

Indicate how much this event or situation happens to you.



include psychologists, therapists, social workers, doctors, nurses, dieticians, etc.

**ORGANIZATION** refers to <u>all staff</u> from the health care organization, whether involved directly with your teen or not. In addition to health care professionals, these people **may include** support staff such as office staff, housekeeper, administrative personnel, etc..

IN THE PAST 6 MONTHS, TO WHAT EXTENT DOES THE <b>ORGANIZATION</b> WHERE YOU RECEIVE SERVICES	To a Very Great Exten t	To a Great Exten t	To a Fairly Great Exten t	To a Mode rate Exten t	To a Small Exten t	To a Very Small Exten t	Not at All	Does Not Appl y
16give you information about the types of services offered at the organization or in your community?	7	6	5	4	3	2	1	0
17have information available about diabetes (e.g., its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
18provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
19have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
20provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	7	6	5	4	3	2	1	0

Indicate how much the event or situation happens to you.

\* Original reference: King, S., Rosenbaum, P., and King, G. Parents' perceptions of care-giving: development and validation of a process measure. <u>Developmental Medicine and Teen</u> <u>Neurology</u>, <u>38</u>(9), 757-772, 1996.



# **GLUCOSE METER DOWNLOAD FORM**

Date & Time on Meter: \_\_\_\_\_ Correct: Y / N

Day/Date	Time	Rd'g	Time	Rd'g	Time	Rd'g	Time	Rd'g	Time	Rd'g
14										
13										
12										
11										
10										
9										
8										
7										
6										
5										
4										
3										
2										
1										
// AD			// A.F.							

# of Days Tested: \_\_\_\_\_ # of Tests: \_\_\_\_\_ Val: \_\_\_

Do you have another meter(s)? Y N If yes, where is this meter kept?

Does any day have 0 readings? Y N If yes, ask, "There are no readings on <days>, can you tell me what happened?"



# HbA1c TEST RESULT SAMPLE LABORATORY TEST RESULT

DTI Laboratories, Inc. PO BOX 1954 Thomasville, GA 31799-1954 DTI Laboratories, Inc. 888.872.2443 229.227.1752 fax John F. Payne, M.D. Medical Director CLIA #: 11D1006555 CAP #: 718287401

A1c Test Result (CPT 83036)

Sample ID # 55477 Client Code: WAYNE ST. UNIV Date Sample Collected: 02/12/07 Date Test Results Reported: 02/21/07

A1c Test Result: 14.1% Mean Blood Glucose: 425 mg/dl Normal Range 4.2 - 6.0% Normal Range 72 - 136 mg/dl

Mean Blood Glucose is derived using the DCCT equation: (% A1c x 35.6 - 77.3) = MBG mg/dl (r) of 0.82.

Each 1 % increase in A1c is a reflection of an increase in Mean Blood Glucose of approximately 35 mg/dl.

A1c test results should be interpreted and target levels set by a healthcare professional.

The American Diabetes Association (ADA) recommends maintaining A1c levels below 7.0%.

## Method of Analysis - HPLC-IE/BA (Multi-Method Procedure) Patent Pending

Linearity of HPLC-IE/BA procedure: 3.82% - 22.2%% CV (Total Precision): 0.525 when the A1c = 5.7% and .038 when the A1c is 10.5% 95% Confidence Interval at 2 SD's: Expected range at 5.7% is 5.65 - 5.77% and at 10.5% is 10.45 -10.59%

\*REFERENCES: DCCT GROUP, NEW ENGL. J. MED: 329, 977-986 (1993) SANTIAGO, J.V., DIABETES, 42, 1549-1554 (1993) DIABETES 1997; 46 (SUPPL 1): 8A, DIABETES CARE 1999; 22 (Suppl. 1): S32-41

THE ABOVE RESULTS WERE OBTAINED BY A MULTI-METHOD ANALYTICAL PROCEDURE CONSISTING OF:

HPLC-IE AND HPLC-BA BOTH METHODS ARE TRACEABLE TO THE DIABETES CONTROL AND COMPLICATIONS TRIAL (DCCT) AND ARE RECOGNIZED BY THE NATIONAL GLYCOHEMOGLOBIN STANDARDIZATION PROGRAM (NGSP).

\*\*\*\* FINAL REPORT\*\*\*\*



# FAMILY INFORMATION

Please tell us about <u>your child</u> :	Vhat is your child's date of birth?				
	*What is your child's gender? O Female (1) O Male (2)				
*When was your child diagnosed with d	liabetes (month/year)?				
What grade is your child in? (circle one of the circle one one one of t	) $10 \ 11 \ 12 \qquad 1yr \ 2yr \ 3yr \ 4yr$ $(13) \ (14) \ (15) \ (16)$ College				
*Is your child Hispanic or Latino? O Yes (1) Native (4)	*What is your child's racial/ethnic background? O Asian/Pacific Islander (1) O American Indian/Alaskan				
	O White/Caucasian (3) O Other (6) please, specify:				
*At T2-T3, if different primary careg the starred items	iver complete form in its entirety; if unchanged, you may omit				
Please tell us about <u>yourself</u> :	*What is your date of birth? *What is your gender? O Female (1) O Male (2)				
What is the highest grade you have com 1 2 3 4 5 6 7 8 9 11yr	pleted? (circle <u>one</u> ) 10 11 12 1yr 2yr 3yr 4yr 5yr 6yr 7yr 8yr 9yr 10yr				
Grade School Hig	(13) (14) (15) (16) (17) (18) (19) (20) (21) (22) (23) College Graduate School				
*Are you Hispanic or Latino? O Yes (1) Native (1)	*What is your racial/ethnic background? O Asian/Pacific Islander (1) O American Indian/Alaskan				
$O \operatorname{No}_{(0)}$	O Black/African American (2) O Bi-racial (5) O White/Caucasian (3) O Other (6) please, specify:				
*What is your relationship to this child?	O Biological parent (1)O Legal Guardian (4)O Step Parent (2)O Foster Parent (5)O Adoptive Parent (3)O O Other (6) please, specify:				
What is your present martial status? widowed (4)	O married to mother/father of this child (1) O single or				
separated or divorced (5)	O married but not to mother/father of this child (2) O				
living with a partner (6)	O single and living with a partner (3) O divorced and				

Which category best describes your family's yearly income, this includes all sources of income which may include employment, social security, other state or federal aid, child support and alimony?

O Less than \$10,000(1)

المنارك للاستشارات

O \$40,000 to \$49,999 (5)

O \$80,000 to \$89,999 (9)



O \$10,000 to \$19,999 <sub>(2)</sub>	O \$50,000 to \$59,999 <sub>(6)</sub>	O \$90,000 to \$99,999 (10)
O \$20,000 to \$29,999 <sub>(3)</sub>	O \$60,000 to \$69,999 <sup>(7)</sup>	O \$100,000 or more (11)
O \$30,000 to \$39,999 (4)	O \$70,000 to \$79,999 <sub>(8)</sub>	O don't know (88)

If you do not know your family's yearly income, what is your family's average monthly income?

Are you employed outside the home? O Yes (1) O No (0)

Who lives in your home (it is their primary residence)?

Relationship to Teen	Age	Financially Supported by You?

# ENDOCRINOLOGY CHART EXTRACTION

Insulin Regimen & Dose: pull from the	CVR dated imm	nediately before DC date			
O Traditional Shots (2-3 mixed injectio	ons)# of injections:				
O Basal-Bolus Injections	# of units of basal/time administered: CHO-to-insulin ratio: TDD (u/kg):				
O Insulin Infusion Pump	basal rate: CHO-to-insulin ratio: TDD (u/kg):				
O Not On Insulin	122 (0, 18).				
Diagnosis:					
Date of Diagnosis (T1 only):	_ Source:	O CHM inpatient records O CVR O Patient Summary List O Other:			
Type of Diabetes: O Type 1 O Type 2	Source:	O CHM inpatient records O CVR O Patient Summary List O Other:			



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#### ABSTRACT

## A SOCIAL ECOLOGICAL PERSPECTIVE ON DIABETES CARE: SUPPORTING ADOLESCENTS AND CAREGIVERS

### by

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### August 2010

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**Major:** Social Work

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The diabetes illness management regimen is complex and demanding, requiring daily motivation and self-control. Adolescents with diabetes face unique risks for which social support may be one protective factor. The importance of social support from family and friends is well documented in the literature. Support for the caregiver and support from the health care provider, conversely, are understudied. These four sources of social support, considered together, span the adolescent's micro-, meso-, and exosystems constituting a social ecological model of social support for diabetes. The primary aim of this study was to test this model. The hypotheses were that each source of social support would independently and positively contribute to illness management when evaluated simultaneously, after controlling for adolescent and caregiver demographics and that illness management behavior would mediate the relationship between social support and diabetes health. A secondary data analysis of adolescents with chronically poorly managed diabetes was undertaken. Structural equation modeling was used to test the study hypotheses. A total of 146 adolescents and their primary caregivers participated in the study. Participants were primarily African American, low-income single-parent families. Results from the analysis did not support the model as hypothesized but did support an alternative model.



In the alternative model, exosystem, but not mesosystem, support was positively associated with microsystem support. Microsystem support was directly related to adolescents' illness management behavior and indirectly related to adolescents' health status. Findings from this study introduce an innovative model of social support for adolescents with diabetes. Supporting the caregiver of adolescents with diabetes may have a beneficial impact on the social support environment in which adolescents perform their daily illness care. A more supportive daily care environment, in turn, may translate to better illness management and better illness health. Social support intervention may be an important strategy for medical social workers, as members of multidisciplinary medical treatment teams, treating adolescents with diabetes and their families.



### AUTOBIOGRAPHICAL STATEMENT

April earned her Bachelor of Arts degree from the University of Michigan in 1997. April's undergraduate studies concentrated in the area of Sociology with a specialized interest in the area of Social Inequality and Criminal Justice. April began her professional career as a Foster Care Worker at Lutheran Social Services of Michigan. April was a case manager for southeastern Michigan families who had children in out-of-home care for reasons of child abuse or neglect. Less than one year after acquiring this position April was promoted to Senior Foster Care Worker. This new position enhanced her responsibilities to include the training of new case mangers as well as assisting with the enhancement of the agency's services.

April left this position in 1999 to pursue her Master's in Social Work degree at the University of Michigan. While pursuing her Master's degree, April worked as a Family Services Worker at Boysville of Michigan. To fulfill the practicum requirement of the Master's program, April also interned in Boysville of Michigan's Program Evaluation Department. She successfully completed and earned her M.S.W., focused on Social Policy and Program Evaluation with Children and Youth, in sixteen months. Boysville of Michigan's Program Evaluation and swiftly promoted her to Program Evaluation Supervisor.

After a year and a half as the Program Evaluation Supervisor, April was hired as a Research Assistant/Project Manager by Wayne State University's School of Medicine. April worked as a Project Manager on a NIDDK-funded, RO1 randomized clinical trial for four years before entering the doctoral program in the fall of 2006. This dissertation study represents the culmination of her doctoral training.

