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A warm watchful eye: parental emotional support and monitoring in multisystem therapy for youth with diabetes

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A WARM WATCHFUL EYE: PARENTAL EMOTIONAL SUPPORT AND MONITORING IN MULTISYSTEM THERAPY FOR YOUTH WITH DIABETES

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CHAPTER 1

INTRODUCTION

Diabetes is the fifth leading cause of death for Americans, with 1.5 million people being diagnosed with the disease (ADA, 2011). Of these, 130,000 are children and adolescents who have the disease. Healthcare costs for diabetes related treatment are burdensome, estimated at $132 billion annually (ADA, 2003). People with diabetes are also at higher risk for heart disease, blindness, kidney failure, extremity amputations, and other chronic conditions.

Living with diabetes requires intensive daily management and treatment, including daily blood glucose testing and insulin management through multiple insulin injections, carbohydrate counting, regular exercise and frequent contact with healthcare providers (ADA, 2011). Insulin regimens require constant individual tailoring to accommodate the developmental level of the child, as well as lifestyle and changing insulin needs (Mortensen et al., 1998). With three-fourths of type 1 diabetes being diagnosed in youth less that 18 years olds, further special accommodations need to be considered for children and adolescents (ADA, 2011).

The purpose of this study is to examine a multisystem psychotherapeutic intervention for youth with type 1 diabetes and their families, aimed at improving the health care status of the youth. Of particular interest is the extent to which changes in parenting behaviors, specifically monitoring diabetes care completion and providing emotional support to the youth, improve health care status. Addressing metabolic control through this type of family therapy is thought to increase parent's social support, thus aiding diabetes care, taking advantage of family resources to improve the health of

their child with diabetes. Parents play a pivotal role in the healthcare and support structure for their children. Therefore, understanding the ways in which parents can optimally help diabetes is a key part of improving the health status of their child.

Diabetes Care

Optimal diabetes management for children includes performing multiple self-care behaviors throughout the day. First, youth must complete multiple blood glucose tests throughout the day, both to adjust their insulin dose as well as to monitor blood glucose level. Insulin must also be taken several times per day, either by injection or by pump (Silverstein et al., 2005). The type of insulin used varies across individuals and can include rapid-, short-, intermediate-, and/or long-acting insulin. In addition, nutritional intake needs to be closely monitored, particularly intake of carbohydrates, and adjustments made to insulin dosing as needed. Daily activity and exercise also must be monitored for their effects on blood glucose levels. Adolescents have more problems with managing diabetes care than younger children or adults (Hamilton & Daneman, 2002; Miller-Johnson et al., 1994; Wysocki, 1993). Thus, while diabetes care is complex, time consuming, and effortful even for adults, it is even more so for adolescents, who are developing independence and personal responsibility for their own self-care.

Short-term complications of poor diabetes management include hypoglycemia, which could result in neurological abnormalities such as reduction of mental efficiency and seizures. Diabetic ketoacidosis (DKA) is a potential fatal consequence of missed insulin doses that results from hyperglycemia and ketone buildup in the blood. DKA is the leading cause of death in children with diabetes. Long-term complications of poor

diabetes management for children include poor growth, weight loss, and delay in pubertal and skeletal maturation. In addition, poor metabolic control can result in chronic complications due to prolonged damage of the blood vessels, resulting in kidney damage (nephropathy), nerve damage (neuropathy), and retinal damage (etinopathy).

The landmark Diabetes Control and Complications Trial (DDCT, 1993, 1994) showed that diabetes related complications can be reduced through intensive diabetes management. Overall health status in persons with diabetes is assessed by metabolic control, which is routinely measured by hemoglobin A1c (HbA1c), a laboratory test of glycated hemoglobin that indicates average blood glucose control over the previous 2-3 months. In addition to indicating general health status, lower HbA1C is associated with higher quality of life for adolescents (Hoey et al., 2001). Maintaining adequate metabolic control through daily diabetes management is crucial for healthy living for youth with diabetes. The complexities of management and anticipating complications highlight the need for guidance from responsible adults.

Youth share the responsibility of daily care management with healthcare professionals and their parents. The American Diabetes Association (ADA) recommends that a team of healthcare professionals, including physicians, nurse educators, psychologists, dieticians, physical therapists, and podiatrists, monitor the health of youth with diabetes. However, parental involvement in diabetes care is necessary for children and adolescents to maintain adequate metabolic control. Higher levels of shared diabetes care responsibility between youth and their parents are related to better metabolic control (Follansbee, 1989). Younger children require a higher degree of parental involvement in diabetes care. As children develop into adolescents,

they are able to take on more responsibility for their care (Ingersoll, Orr, Herrold, & Golden, 1986). Although increased personal responsibility is appropriate over time, it is recommended that parents still maintain a high level of involvement in the care of adolescents, in particular making insulin adjustments and meal planning (Silverstein et al., 2005; Follansbee, 1989; LaGreca, Follansbee, & Skyler, 1990). A gradual transition to independent self-care is ideal in which adolescents gain responsibility in small increments that match their current ability (Silverstein, 2005; LaGreca, Follansbee, & Skyler, 1990; Palmer et al., 2004). For a successful transition to self-care, it is important to find a division of responsibility that is comfortable for everyone involved (Seiffge-Krenke, 1998).

Metabolic Control in Adolescence

Adolescents have poorer metabolic control than either children or adults, even with traditional supports that have been successful for adults (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997, Miller-Johnson et al., 1994; Wysocki, 1993). According to a survey of patients with diabetes worldwide, 29% of adolescents had HbA1c levels that were higher than those recommended (Mortensen et al., 1998).

A variety of factors affect metabolic control in adolescents. Pubertal maturation causes decreased insulin sensitivity, due to hypersensitivity to growth hormones (Bloch Clemons, & Sperling, 1987; Hamilton & Daneman, 2002). In addition, rapid growth can increase the need for insulin dose adjustments. However, a variety of factors are also linked to declines in diabetes management during the adolescent period, including the degree of cognitive maturation (Brewster, 1982, Ingersoll et al., 1986), adolescent risk-taking behavior (Anderson et al., 1997, Weissberg et al., 1995), and demographic

factors, such as single parent homes and parent illness (Anderson et al., 1997). This study focuses on another important factor affecting adolescent diabetes management, parenting behavior.

Factors Affecting Adolescent Diabetes Management

A substantial body of research shows that family relationships are related to diabetes management during adolescence. Positive family communication and conflict resolution skills strongly predicts of better metabolic control (Wysocki, 1993). Youth with diabetes in more cohesive families have better metabolic control and diabetes management than youth in families who are less cohesive (Duke et al., 2008; Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992). As previously noted parental involvement is necessary throughout childhood and adolescence to assure appropriate self-management and metabolic control (Follansbee, 1989). It predicts management of diabetes care and metabolic control (Palmer et al., 2010; Wiebe et al., 2005). In addition to other biological and psychological factors, parental involvement and appropriately shared responsibility of parents and youth is highly correlated with metabolic control (Anderson, Holmbeck, Iannotti, McKay, & Lochrie, 2009, Palmer et al., 2004).

In most previous research, “involvement” is operationalized by measuring how much of the diabetes care of the youth is completed by the parent versus the youth (Anderson et al., 1990, Harris, Greco, Wysocki, Elder-Danda, & White 1999). This is helpful in understanding how care responsibility is shifted from parents to youth self care, but it does not provide an understanding of the process by which parents effectively maintain involvement through this transition in care. One potential way

parents can remain involved during this shift to youth self-care, is by monitoring their children in the completion of diabetes care, that is, allowing their youth to complete care task independently, but supervising to ensure that all care is completed. Another way can be providing emotional support to encourage their children to manage their diabetes care themselves. The current study evaluates the effects of a family-based treatment on parental involvement with youth's diabetes care. It specifically investigates their monitoring and emotional support, and whether such parenting behaviors are related to their children's improvement in metabolic control.

Parental Monitoring

Parents can be involved in diabetes care with the youth by monitoring and supervising their care. Parental monitoring includes a set of parenting behaviors involving attention to their children and tracking of their whereabouts, activities, and adaptations (Dishion & McMahon, 1998). It is more than surveillance and could include any activity that facilitates parents' awareness of the activities of their child. In terms of diabetes care, parental monitoring refers to behaviors that involve information-seeking about the daily diabetes care activities of their children as well as supervision and oversight of those activities (Ellis et al., 2007; Horton, Berg, Butner & Wiebe, 2009). It is distinct from knowledge of whether or not their child is doing their required diabetes care, including activities that allow self-care information to be gathered (Ellis et al., 2007). It is different from parental support, in that it does not include emotional aspects of parenting (Ellis et al., 2008).

Parental monitoring of diabetes care has been identified as a key way that parents can be involved in the facilitation of diabetes care (Berg et al., 2008, Palmer et

al., 2010). Parental monitoring has direct effects upon adolescent diabetes management and through management, has an indirect effect on metabolic control (Ellis et al., 2007, Horton, 2009). Despite the fact that cross-sectional studies show relationships between parental monitoring and diabetes management, no studies indicate that increasing parental monitoring results in improved self-care. The current study is aimed at increasing the understanding of the role of parental monitoring in successful diabetes care for youth.

Parental Emotional Support

Another way parents can be involved in their youths' diabetes care is by providing emotional support. Parental warmth, including affection and supportive parenting, is related to better management of diabetes care (Davis et al., 2001). When parents understand and listen to their children about diabetes and treatment, improved HbA1c is also seen (Waller et al., 1986). Conversely, negative and unsupportive parental behaviors such as nagging, criticism, coercion, and scolding are associated with poor metabolic control of their children's diabetes (Duke et al., 2008; Schafer, McCaul, & Glasgow, 1986). Youth perceive their family as most supportive of their diabetes and treatment when their parents express emotional support, not simply instrumental support (LaGreca & Bearman, 2002). Additionally, higher youth perceptions of parental warmth and caring related to diabetes care, is associated with decreases in DKA episodes (Geffken et al., 2008, Liss et al., 1998).

The particular components of emotional support have been operationalized differently across various research studies. The range includes affective components of understanding and praise, as well as supportive behaviors such as planning activities

that fit with diabetes care goals. The present study examined the affective component of parental support including understanding, listening to their children's concerns, and feeling comfortable expressing feelings to their parents, separate from behavioral aspects of support that can overlap with parental monitoring. Parsing parental involvement into distinct components has not been adequately addressed in the existing literature to date.

Although it is related to parental monitoring, parental emotional support is uniquely important to consider (Dishion & McMahon, 1998; Ellis et al., 2007; Kerr & Stattin, 2000, Palmer et al., 2010). Parental emotional support does not include supervising and overseeing diabetes care as seen in parental monitoring. Rather, it is the affective support of their youth's experience with diabetes. It has been theorized that both support and monitoring allow youth to develop healthy autonomy and therefore acquire and use adaptive coping skills to manage stress.

Parental monitoring and emotional support are identified as distinct and important, therefore the current study sought to understand how a particular intervention affects both components of parental involvement. This includes how the two function independently and together to improve youths' metabolic control. Facilitating optimal parental involvement in diabetes care has become an aim of psychological interventions for youth with diabetes.

MultisystemicTherapy

There have been a variety of family based treatments aimed at improving illness management in youth with diabetes (Delamater, Johnson, Anderson, & Cox, 2001; Kahana, Drotar, & Frazier, 2007), yet many of these treatments did not directly target

parental monitoring or parental emotional support. Although some of these treatments could have increased parental monitoring and/or emotional support from parents, changes in these parenting behaviors have not been measured directly. In contrast, Multisystemic Therapy (MST), adapted for use with youth with diabetes, targets a range of behaviors including parental monitoring and emotional support for their children's diabetes care as a way to improve metabolic control.

Multisystemic Therapy (MST) is an intensive, home- and community-based family therapy originally used with youth who have with serious mental health problems and their families. It primarily focuses on empowering caregivers to provide effective manage many of the challenges presented in keeping their children healthy. It has recently been adapted for use with families that include youth with poorly controlled type 1 diabetes (Ellis et al., 2005). Therapy begins with an assessment of strengths and weaknesses of the family across many systems, e.g. peer groups, school, and health care systems. Then the treatment plan is tailored to best meet the individually identified needs of the family.

The family system is a focus of MST, through various types of interventions. Parental monitoring is targeted by assisting the family in the creation of a regular schedule of diabetes care. This is to be shared between the target youth and his/her parent, increasing direct observations of diabetes management by caregivers, enlisting support from secondary caregivers to observe diabetes care, and setting up other check-in options that fit the family's unique needs. Parental emotional support is addressed by teaching parents more effective parenting techniques that increase

positive parent-child interactions and change negative thought patterns that could hinder parental warmth.

In randomized clinical trials, MST has significantly improved management of diabetes care, and improved metabolic control in youth with poorly controlled (Ellis et al., 2007). However, there is a need to understand the mechanisms that drive effective health psychology treatments (Zazdin, 2008; Rees, 2002; Kolko et al., 2000; Weisz, Huey, Weersing, 1998). The goal of the current study was to determine whether MST improves diabetes related parenting activities, such as monitoring of their children's diabetes care and support for diabetes care, and whether parental monitoring and emotional support act as mediators of improvements in management and metabolic control of the youth's diabetes.

The Current Study

This study sought to understand parental monitoring and emotional support as distinct aspects of parental involvement in diabetes care that could be altered and improved by MST. Understanding the unique contributions of these components of parental involvement can help guide further development of interventions, including MST, to more directly address key elements of the family system that are important to the health of children with diabetes. In addition, the current study was aimed at determining whether parental monitoring and emotional support act as mechanisms of improvement in diabetes management.

Given the research to date, this project hypothesized that youth in the MST group would report significantly greater increases in emotional support from their caregivers from baseline to post treatment and six-month follow-up, compared to a telephone

support control group. Additionally, youth in the MST group were expected to report significantly greater increases in parental monitoring. In particular this was expected to include more direct observation of diabetes care completion from baseline to post treatment and six-month follow-up compared to that seen in a telephone support control group. Also, increases in parental monitoring and support from baseline to six-month follow-up were expected to be related to improved diabetes management for all youth in the trial, which in turn would be related to improved metabolic control.

CHAPTER 2

METHOD

Participants

The participants for this study come from a large randomized clinical trial of Multisystemic Therapy for youth with poorly controlled diabetes (Ellis et al., 2005). Adolescents with chronic poorly controlled diabetes and their families were recruited from the endocrinology clinic of a children's hospital located in a major Midwestern metropolitan area. To be eligible, participants had been diagnosed with insulin managed type 1 or type 2 diabetes for at least 1 year; had an average HbA1c of ≥ 8% during the year before study entry, as well as a most recent HbA1c ≥ 8%; be 10.0 –18.0 years old, had sufficient mastery of English to communicate with therapists and complete study measures, and had no reported moderate/severe mental retardation or psychosis.

The sample of 146 adolescents was randomly assigned to either a Multisystemic Therapy (MST) (n = 74) or a telephone support condition (n = 72). Demographic characteristics of the youth are shown in Table 1. The majority of the sample was African American. The average age of participants was 14 years old. The average HbA1c in the sample was 11.68 and the average time since of diagnosis was 4 years and 3 months.

Design

The study was a randomized controlled trial with a repeated-measures design. Families randomly assigned to MST received 6 months of home-based psychotherapy in addition to standard medical care, whereas families randomly assigned to the control

condition received weekly telephone support, described below, and standard medical care. Randomization into the treatment or control condition was done immediately after baseline data collection. To ensure equivalence across treatment condition, randomization was stratified by level of HbA1c and Body Mass Index, an indicator of body fatness, at the baseline visit. A research assistant who was blind to treatment condition collected data at pre-, post treatment and 12-month follow-up in home visits.

Multisystemic Therapy Condition

The treatment intervention, Multisystemic Therapy (MST), is an intensive, family-centered, community- based treatment originally designed for use with adolescents with serious antisocial behavior. The therapy targets the various systems in which youth and their family's function, creating individualized treatment plan. Treatment fidelity is maintained by adherence to nine treatment principles.

The principles of MST include 1) assessing the fit between the problem and the systemic context, 2) emphasizing the strengths to drive change, 3) promoting responsible behavior among family members, 4) remaining present focused with action oriented steps toward specific problems, 5) targeting sequences of behavior within or between multiple systems that maintain the problem behavior, 6) providing developmentally appropriate interventions, 7) requiring daily or weekly effort by family members, 8) evaluating efficacy from multiple perspectives of how providers overcome barriers to diabetes care, 9) promoting generalization and long-term maintenance of change that empowers caregivers to address family members needs across multiple systemic context, which are seen as interconnected. Therapists and supervisors received formal, week-long training in MST techniques. Treatment fidelity was

maintained through weekly on-site clinical supervision and weekly phone calls with an MST expert consultant, as well as formal fidelity ratings of session audiotapes.

Therapists met with the family a minimum or two to three times per week during the early parts of treatment. Treatment ended when the goals of therapy were met according to both the therapist and the family. The average length of treatment in this study was 5.6 months. Therapists drew upon a menu of evidence-based intervention techniques, including cognitive-behavioral therapy, parent training, and behavioral family system therapies.

Therapy targeted adherence-related problems within the family system, peer network, and the community system. Family interventions focused on improving parental involvement, monitoring, and discipline concerning the diabetes regimen of the youth, developing family organizational routines such as regular meal times; and teaching caregivers to communicate effectively with each other about the medical regimen of the youth. Peer interventions included enlisting the active support of friends and classmates to help youth stick to his/her diabetes regimen (Ellis et al., 2007). School interventions included improving family–school communication about the diabetes care needs of the youth and completing diabetes care behaviors at school. Examples of this are such things as having school personnel report the youth's blood glucose readings from school meter to parents weekly and finding a private place for the youth to test blood glucose. At the community level, interventions targeted developing strategies to monitor and promote the diabetes care of the youth while he/she is outside the immediate family, i.e., school (as described above), extracurricular activities, and visiting extended family members. Interventions within the health care system included

helping the family resolve barriers to keeping appointments and working with the family and the diabetes treatment team to promote a positive working relationship. Therapists also routinely accompanied families to their medical appointments. Further details of the treatment procedure are described in (Ellis et al., 2012).

Telephone Support Control Condition

Youth randomly assigned to the Telephone Support (TS) condition were called weekly, with conversations focused on support for diabetes care. The therapist assigned to the youth visited families in the TS condition before beginning treatment, at which time introductions were made between youth, parents, and their therapist. During this visit, the call routine was explained. A master's level therapist (2) or doctoral student (4) in clinical psychology or social work who used a client-centered, non-directive counseling approach made weekly 30-minute phone calls to the youth for approximately six months. The phone calls provided support regarding the chronic medical condition of the youth. This included assessing adherence to treatment regimen, supporting the youth to brainstorm solutions to problems they identified with their diabetes care. Treatment fidelity was maintained by requiring therapist to use of a treatment manual, and a semi-scripted structure for phone call content. Therapists were trained beforehand to competency in therapeutic methods. In addition there were ongoing oversight via weekly supervisory sessions and supervisors reviewed phone call audiotapes. Participants were not restricted from receiving outside mental health services during the telephone support.

Measures

To measure youth's the perception of emotional support from their primary caregiver for assisting with diabetes care of the youth, four items from the Diabetes Social Support Questionnaire-Family (DSSQ-Family) (LaGreca & Bearman 2002) were used. These four items were selected to reflect the emotional components of support, including the youth feeling understood by their caregivers and being comfortable expressing feelings about diabetes care with their caregivers. Youth report the frequency of each behavior on a five-point scale from "never" to "at least once a day" and the supportiveness of each behavior on a three-point scale from "not at all" to "very". A frequency score was used for each behavior. These four items had high internal reliability (alpha = .83).

To measure parent monitoring of diabetes care, the Parental Monitoring Diabetes Care (PMDC) was given, which is an 18-item questionnaire that measures the frequency of parental monitoring and direct supervision of diabetes tasks. Caregivers and the youth completed parallel measures. The response format was a five point scale from "more than one a day" to "less than once a week." Higher scores indicate higher levels of parental monitoring. Subscales of the PMDC further specified types of monitoring such as direct oversight of diabetes management, nonadherence, diet, checking blood glucose, and supervision of the availability of medical supplies. Items have been previously shown to have adequate internal reliability (alpha = .71 for adolescents and .80 for parents) in a similar sample (Ellis et al., 2008). In this sample, the internal reliability was adequate (alpha = .75 for parents and alpha = .55 for adolescents) and parent and adolescent reports were significantly related to parent report (r = .65, p < .001).

Diabetes management was measured by both subjective report of the parent and youth and an objective measurement. The Diabetes Management Scale (Schilling, Grey, & Knafl, 2002) is a 23 item self-report questionnaire that assess a range of the components of good diabetes care, including insulin and dietary management, blood glucose monitoring, and response to symptoms. Youth and parent indicate on a 0-100 scale "what percent of the time do you…." Responses were summed to create a score of overall adherence. The instrument has demonstrated adequate reliability and validity (Schilling, Grey, & Knafl, 2002). Parallel forms completed by the parent and youth were analyzed. In addition, the frequency of blood glucose testing, a specific adherence behavior, was obtained directly from the blood glucose meter of the youth for the previous 14-day period preceding data collection. The average daily testing frequency for these data were also analyzed.

Metabolic control was measured by HbA1c levels, which provided a measure of average blood glucose over the previous 2- to 3-month period. Higher HbA1c indicates poorer metabolic control (Ellis et al., 2007). HbA1c levels were collected using an Accubase HbA1c test kit during home data collections.

CHAPTER 3

RESULTS

Data Cleaning and Management

The data were screened for accuracy of input, nonrandom missing data, univariate and multivariate outliers, and normality. One univariate outlier was found with respect to the HbA1c variable (z = 3.38). Nevertheless, this participant was included in the analyses due to the medical accuracy of the measure. No more than 7% of the data were missing for any variable.

As expected, given the nature of the measure and study recruitment criteria, HbA1c had significant positive skew at all three time points, measured by dividing the skew statistic by the standard error of skew. A square root transformation was conducted on this variable at all three time points, yielding normal distributions for all three variables. In addition, total parental monitoring reported by the caregiver at baseline and immediately post treatment had significant negative skew and a square root of (k-x) transformation was conducted yielding normal distributions. Analyses were conducted with both the raw data and the transformed data, and the findings were similar. Therefore, the raw scores were used in all analyses for ease of interpretation.

Analyses estimated missing data using regression. The results for both the estimated data and the original data were similar. Additionally, data from participants who did not complete three or more sessions (n = 3) were removed and were re-analyzed, showing no significant differences in the results. Due to the lack of differences in these findings, results from all participants were reported in the following analyses, without computing missing values.

Preliminary Analyses of Measures

Bivariate correlations between baseline parental involvement variables were computed to check the independence of measures that assessed similar constructs. Parental emotional support measured by the DSSQ and parental monitoring measured by the PMDC-caregiver and PMDC-youth were not significantly correlated (caregiver report: r = -.14, p = .09, youth report: r = -.11, p = .19) suggesting that the PMDC and DSSQ measured different dimensions of parental involvement.

Likewise, correlations between baseline diabetes outcomes were computed to check the independence of these measures. HbA1c was moderately negatively correlated with the average daily number of blood glucose tests (r = -.43, p < .001) and to total adherence reported by parents (r = -.22, p = .007) and youth (r = -.35, p < .001) on the DMS at baseline. Average daily number of blood glucose test calculated from the glucose meter download was moderately related to total adherence reported by parents (r = .37, p < .001) and youth (r = .53, p < .001). The magnitude of these correlations suggests the diabetes outcomes are related in the expected way and measure different dimensions of diabetes care.

Main Hypothesis Testing

To test the hypotheses that participants in the MST condition would show greater increases in emotional support (DSSQ) and parental monitoring (PMDC) than the participants in the TS condition, repeated measures analyses of variance (RM-ANOVA) were used. Separate analyses were conducted to examine the relationship from baseline to post treatment and baseline to six-month follow-up. Both the Total Monitoring scale and the Direct Observation sub-scale of the PMDC were used to

measure all monitoring behaviors and parents presence during diabetes care behaviors, respectively.

Emotional Support. From baseline to immediate post treatment, there was no significant main effect of time (F[1,137] = 1.85, p = .18) and the interaction between group and time was not significant (F[1,137] = .03, p = .87), demonstrating that the two groups did not experience differential change over time in emotional support.

From baseline to six-month follow-up, there was a significant main effect of time (F[1,135] = 4.04, p = .05). Contrary to hypothesis, youth in both conditions reported decreases in emotional support from baseline (M = 2.79; SD = 1.48) to follow-up (M = 2.54; SD = 1.47). There was no significant group by time interaction (F[1,135] = .29, p = .59).

Parental Monitoring-Youth Reports. Youth reports of total parental monitoring measured by the PMDC-youth from baseline to immediately post treatment showed a significant main effect of time (F[1,144]= 8.12, p = .005) with both TS and MST groups reporting increased parental monitoring over time. However, there was no significant group by time interaction based on youth report (F[1,144] = .32, p = .57). Similar findings emerged when the period from baseline to six-month follow-up was considered. Total parental monitoring as reported by the youth showed a significant main effect with increasing parental monitoring over time (F[1,144] = 22.21, p < .001) but there was no significant difference between the MST and TS groups (F[1,144]= .01, p = .94). Youth reports of direct oversight of diabetes care by caregiver measured by a subscale of the PMDC-youth from baseline to immediate post treatment showed no significant main effect of direct observation (F[1,144] = .15, p = .70) and no difference between the MST

and TS groups (F[1,144] = 1.18, p = .23). Similarly from baseline to follow-up, there was no significant main effect of direct observation (F[1,144] = 1.78, p = .19) and no difference by group (F[1,144] = .14, p = .71).

Parental Monitoring-Caregiver reports. Caregiver reports of total parental monitoring measured by the PMDC-caregiver showed a similar pattern to those found for youth-reported parental monitoring (PMDC-youth). From baseline to immediate post treatment, there was a significant main effect for time such that both TS and MST parents had increased monitoring (F[1,144] = 24.79, p <.001). However, there was no significant difference between MST and TS groups (F[1,144] = .20, p = .66). Similarly for caregiver reports from baseline to follow-up, there was a significant main effect of time (F[1,144] = 45.64, p < .001) with no difference between MST and TS groups (F[1,144] = .02, p = .90). From baseline to immediate post treatment showed a significant main effects of time when caregivers reported direct observation of diabetes (F[1,144] = 16.32, p < .001) with direct observation increasing over time for both groups. However, there was no significant differences between the MST and TS groups in direct observation from baseline to post treatment (F[1,144] = .004, p = .95). Additionally, from baseline to follow-up, there was a significant main effect of direct observation (F[1,144] = 25.16, p < .001) but no significant differences between MST and TS from baseline to follow-up (F[1,144] = .03, p = .88).

Relationships between changes in parental involvement and diabetes outcomes. Unstandardized residual change scores were correlated to test the hypothesis that changes in parental emotional support (DSSQ) and parental monitoring (PMDC) would be related to changes in adherence (DMS), metabolic control (HbA1c) and frequency of

blood glucose testing in the entire sample. Unstandardized residual change scores were first created by regressing a post treatment variable onto its corresponding baseline score. For instance, in the case of emotional support, a residualized change score was created by regressing post treatment emotional support onto baseline emotional support. The change score is thus a measure of change in emotional support that is not accounted for by baseline emotional support.

These analyses revealed that changes in parental emotional support were not related to changes in adherence, metabolic control or frequency of blood glucose testing. See Table 2.

Changes in overall parental monitoring reported by parents and youth measured by the PMDC did not relate to changes in DMS total adherence, HbA1c or frequency of blood glucose testing from blood glucose meters. However, further analysis of the subscales of the PMDC revealed some significant relationships from baseline to follow-up. Consistent with the hypothesis, increases in Parental Supervision of the Availability of Medical Supplies reported by the youth were correlated with increases in total adherence reported by the caregiver and the youth (DMS-caregiver r = .21, p = .01, DMS-youth r = .25, p = .003). Similarly, increases in Parental Supervision Availability of Medical Supplies reported by the caregiver were correlated with total adherence reported by the caregiver (PMDC-caregiver r = .23, p = .006). Contrary to predictions, increases in Parental Oversight of Diet reported by the youth were correlated with decreases in total adherence reported by the youth and the caregiver (PMDC-youth r = -.17, p =.05; PMDC-caregiver r = -.25, p = .004) and increases in Direct Oversight of

Diabetes Management Behaviors reported by the youth were correlated with decreases in the average daily blood sugar tests (r = -.24, p = .005). See Table 3.

Additional Exploratory Analyses

Contrary to the main hypotheses, the treatment group did not show greater increases in parental monitoring or emotional support and changes in emotional support did not relate to changes in measures of diabetes outcomes. Changes in some subscales of parental monitoring appear to be related to improved self-reported adherence and increases in the average daily blood sugar tests. Therefore, additional exploratory analyses were conducted to determine if parental involvement changed over time for all youth depending on the age of the child.

Emotional support and parental monitoring changing by age. To test for differences in parental involvement based on the age of the youth, RM-ANOVAs were conducted to determine if changes in youth reports of emotional support (DSSQ) and parental monitoring (PMDC) provided by the caregiver differed by age group. These analyses were run for the entire sample. Age was divided into three developmentally relevant groups: preteen (10.0-12.9 years), younger teenagers (13.0-16.9) and older teenagers (17.0-18.0).

There was a significant interaction between time and age from baseline to post treatment in emotional support (F[1,2] = 3.6, p =.03). Paired samples t-tests showed that preteens and older teens showed no changes in emotional support (t[1,44] = .57, p = .57 and t[1,16] = -1.5, p = .13)), while younger teens experienced significant decreases in emotional support from baseline to post treatment (t[1,71] = 2.98, p = .004). However, time and age did not significantly interact with respect to emotional

support when the period was from baseline to six-month follow-up (F[1,2] = 1.64, p =.20). Additionally, there were no significant interactions between youth age and parental monitoring (PMDC) from baseline to either immediate post treatment or six-month follow-up.

CHAPTER 4

DISCUSSION

Although MST has been shown to be effective in improving diabetes adherence and metabolic control, the mechanisms of the improvements are still unknown (Ellis et al., 2012). Parental involvement is a focus of the intervention and was hypothesized in the current study to contribute to improvements in diabetes care. In past research, parental monitoring has been considered the primary parental involvement variable of interest as it has been associated with diabetes management and metabolic control (Palmer et al., 2010; Wiebe et al., 2005). Therefore, parental monitoring was one variable examined in this study. However, there are other elements of parental involvement that could also be important in diabetes care. For instance, parental emotional support has also been associated with diabetes management and metabolic control (Davis et al., 2001, Waller et al., 1986), Nevertheless, no studies have yet examined whether either of these parental involvement variables are directly affected by participation in MST. Thus, the purpose of this study was to examine the extent to which MST improved parental monitoring and emotional support relative to a telephone support control condition.

Parental Monitoring

It was hypothesized that families in the MST group would report larger increases in parental monitoring than families in the telephone support group. However, results of the present study did not support this hypothesis. Surprisingly, both groups experienced similar increases in total scores of parental monitoring from baseline to post treatment and from baseline to follow-up. Parents in both groups also reported increases in direct oversight of diabetes care behaviors. These findings suggest that parental monitoring is

not the mechanism of improved diabetes adherence and metabolic control seen in MST. Whereas parental monitoring is an important aspect of MST, it is one of numerous areas addressed in the therapy. One of the unique aspects of MST is the larger systems approach to improving diabetes care and it is possible that a change in only one area, like parental monitoring, does not change diabetes care behavior all by itself.

It was also hypothesized that increases in parental monitoring for all youth would be related to increases in diabetes care behaviors. Parental monitoring of availability of diabetes care supplies was related to adherence reported by the parent and youth from baseline to follow-up. However, contrary to hypothesis, direct oversight of diabetes care and monitoring of diet were negatively related to adherence and the average blood glucose tests from baseline to follow-up. Together, these changes suggest that the various types of parental monitoring impact diabetes care behaviors in different ways. Previous literature on parental monitoring has focused on overall parental monitoring as it relates to diabetes outcomes, but has not yet examined the differences between the various types of parental monitoring and diabetes outcomes.

There could have been increases in parental monitoring for both the MST and TS groups for several reasons. One potential reason that MST did not increase more than the telephone support groups is that the youth were selected for the treatment study because they were identified as having poor metabolic control. Parents whose children are in poor control could have increased motivation to supervise their child's diabetes care. Recruitment and enrollment in the study could have increased their awareness of or level of concern regarding their child's health status and caused increases over the duration of the study, regardless of the type of treatment the family received. Another

possibility is self-report bias. Parents understand that monitoring their youth's diabetes care is socially desirable and medical personnel in diabetes clinic often encourage increased monitoring when youth's metabolic control is poor. Therefore, parents could have responded in such a way that reflected increases in monitoring regardless of their actual monitoring behavior. In this study, parents and youth could be reporting increases in parental monitoring, in both groups, because they are aware that it is advisable for parents to be involved and thee family wants to be viewed favorably by the therapist.

The groups could also have increased in parental monitoring for different reasons. For example, the MST group could have increased parental monitoring due to direct discussions with therapists and efforts to improve diabetes related monitoring that are part of MST. Families could be actively addressing barriers to the parent being able to monitor diabetes care such as conflict with the child, fitting monitoring into an already busy schedule, and helping the youth build responsibility. On the other hand, parents in the telephone support group could have increased parental monitoring for other reasons. It has been shown in previous studies that minimal contact from the health care team, like phone calls and text messages, can improve diabetes self-efficacy and adherence (Howells et al., 2002; Franklin, Waller, Pagliari & Greene, 2006). Parents in the telephone support group in this study could increase their monitoring as a result of increased reminders of diabetes care through telephone calls to the youth.

Emotional Support

Findings from this study suggest that MST did not improve parental emotional support more than the telephone support condition. In fact, the findings suggest that

there was a decrease in emotional support for both groups, from baseline to post treatment. Emotional support is not a mechanism of improved diabetes adherence and metabolic control seen in MST. Whereas emotional support has been shown in other research to be important in the adjustment of youth with diabetes (Davis et al., 2001, Waller et al., 1986), it was not related to diabetes care behavior in this sample.

There could be no differences between the MST and telephone support group with regard to emotional support, because neither treatment effectively addressed the affective support from parents. Previous research suggests that families with youth who are hospitalized for poor metabolic control have lower diabetes related warmth (Liss et al., 1998). In this sample of youth with poorly controlled diabetes, therapists and families could have been more focused upon ensuring that youth completed diabetes care through changes in instrumental parenting behaviors than affective parenting behavior.

Additionally, MST addresses various systems in the life of the family and youth. Youth in the MST group could show changes in emotional support for their diabetes from other sources, such as peers, friends, siblings and/or extended family members. It is conceivable that increased emotional support from other significant people would be related to changes in diabetes outcomes. Previous studies suggest that adolescents with diabetes feel more emotional support from peers with regard to diabetes care, whereas younger children perceive more support from caregivers (La Greca et al., 1995, Pendley et al., 2001). In one previous study with MST for youth with diabetes, support from the primary caregiver did not increase for youth receiving MST but support from secondary caregivers did increase significantly (Ellis et al., 2007). Therefore,

emotional support more broadly defined to include parents, peers and other significant people in the life of the youth could be increased in MST.

The similarity of reports in families in the MST and TS groups for both parental involvement variables suggest that parental monitoring and affective support could have been too narrowly defined as measures of parental involvement. MST begins with an individualized assessment of barriers to diabetes care that then guides treatment. It is possible that for some families, low parental monitoring or emotional support were not the most salient barriers to completing diabetes care and therefore these factors were not directly addressed in treatment for some families. To better capture the various individualized barriers of the families, measure that captures changes in other aspects of parenting could have been needed. This could include other important aspects of parenting such as communication style, discipline, and problem solving. It is also possible that changes in a single system, such as family functioning or parenting, are not the mechanism for change in MST as adapted for youth with diabetes.

Additional analyses were conducted to examine the effect of age over time. These results showed that young teenagers report decreases in emotional support, while pre-teens and older teenagers do not report changes in emotional support. Although the sample size did not allow for a statistical comparison between the two groups, visual inspection of the data suggest that MST could also increase emotional support from caregivers for older teens compared to minimal change in the TS group, whereas preteens and younger teenagers appear to decrease in both groups. This is consistent with previous research finding that younger youth experience fear, frustration, lack of trust in youths ability to complete care and feel their perspective and

effort are discounted in conversations with caregivers regarding diabetes care (Ivey, Write, Dashiff, 2009). The difference in the reports of youth of different ages could also contribute to difficulty in accurately measuring emotional support because youth could understand the items differently depending on their cognitive abilities and life experiences.

Clinical Implications

The current findings have applications to clinical settings. This study showed a relationship between changes in parental monitoring of medical supplies and adherence. Taken together with other studies that have shown overall parental monitoring is related to diabetes outcomes, it remains important to clinically target parental monitoring for youth with diabetes (Ellis et al., 2007). As noted previously, MST and TS are effective in increasing parental monitoring. MST was favored to TS to improve diabetes adherence and metabolic control in other studies. The cost and personnel needed for MST could create a challenge to provide this type of therapy in all geographic areas. Future research could address whether telephone support could be an option for families to increase parental monitoring when MST is not an option. In the hectic pace of the clinic and hospital setting, health care providers often do not have time to talk to parents about the importance of parental monitoring until the youth presents with uncontrolled diabetes. Although it is not as comprehensive as MST, perhaps telephone support provided by therapists could assist families incorporate parental monitoring during particularly challenging times such as the time of diabetes diagnosis, the transition to adolescents, or times that families report having particular trouble managing diabetes care.

Limitations

There are a few limitations to this study. First, all participants were selected based upon having poorly controlled diabetes, which limits the generalizability to youth with adequately controlled diabetes. Findings from this study suggest preventative steps for youth who are at risk by improving parental monitoring but further studies would be needed to confirm these hypotheses with youth of various levels of diabetes control. Secondly, the wide age range makes it difficult to universally define optimal levels of parental monitoring and emotional support for children at different developmental stages, both cognitively and emotionally. As youth seek to become more independent and assume more responsibility, the varied qualities of ideal emotional support and monitoring from parents could not be captured by the current measures. Third, self-report measures, such as the measures of parental monitoring and adherence used in the present study, are highly susceptible to self-report bias. Parents and youth could understand the importance of these behaviors and could not want to have others evaluating or judging their family when they are struggling. This may lead too reporting higher levels of the behaviors viewed as desirable and could be less accurate compared to observational or biological measures.

Future Directions

The primary focus of psychological interventions for diabetes has been to improve health outcomes, yet overall adjustment and psychological functioning are also important. In this study, changes in emotional support were not related to changes in diabetes adherence and metabolic control, but changes in emotional support could be related to important psychological outcomes such as emotional adjustment to diabetes,

anxiety, depression, or quality of life. Previous studies have shown that parental warmth is related to depression symptoms and diabetes related quality of life in youth with diabetes (Graue, Wentzel-Larsen, Hanestad, Sovik, 2005; Whittmore et al., 2002). Parental support for youth with other chronic illness, such as rheumatic disease, has been related to depression and anxiety (Weiss et. al, 2002). To fully understand the impacts of both MST and the telephone support groups, future research may need to assess outcomes across larger domains of functioning. Additionally, other sources of emotional support in the lives of the youth should be examined. Youth report other sources of emotional support such as friends and significant others and the perception of this type of support and the implications to diabetes adherence should be explored further.

Furthermore, adequately defining emotional support experienced by youth with chronic illness has presented challenges. The measurement of emotional support in this study could also contributed to the surprising findings that changes in emotional support were not related to diabetes outcomes for the youth in either the telephone support or MST groups. Previous studies have noted the difficulty of accurately measure parental attempts to be involved with the youth and separate emotional support from parental monitoring (Ellis et al., 2008). It is also important to account for cognitive differences in youth that impact their experience of emotional support. Using alternative measurement approaches, such as semi-structured interviews or behavioral ratings, could allow researchers to more adequately evaluate these end points.

Continued work is needed to understand the perceptions and reactions of youth to parental monitoring. It has been shown that the perception of social support reported

by youth is important to predicting outcomes of treatments (Geffken et al., 2008, Liss et al., 1998). It is potentially true for other forms of parental involvement, such as parental monitoring. Creating a safe and supportive environment that facilitates completion of diabetes care could be a foundational step for families under the stress of managing the chronic illness of the youth. If youth feel the challenges they face with diabetes are understood they could be more receptive to more direct parental supervision of their diabetes care. When the emotional support is lacking, the same types of increases in supervision could be experienced as nagging or over-control and rejected by the youth.

To identify mechanisms of treatment effect in MST, other factors in the effectiveness of treatment should be examined, including peer support. One of the unique qualities of MST is the comprehensive systems assessment and highly individualized treatment. Future studies should aim to identify the most important components of treatment and how to combine these components to maximize treatment effectiveness.

Conclusion

In sum, the findings from the current study suggest that parental monitoring of diabetes care increased in families receiving both MST and a telephone support condition. In addition, the results showed that increases in one type of parental monitoring, supervision of medical supplies, resulted in increased adherence. This study increased our understanding of the specific mechanisms through which MST might produce changes in parental involvement that are relevant to diabetes outcomes. Continued research is needed to determine if the efficacy of MST over other interventions for improving adherence and metabolic control shown in other studies

(Ellis et al, 2005; Ellis et al., 2012) are due to changes in other parenting behaviors or changes in other systems targeted by the intervention.

Table 1

Demographic characteristics of youth and their families

Characteristic	Mean (SD)
Youth age (years)	14.17 (2.29)
Parent age (years)	41.41 (7.89)
Youth Gender	
female	56.2%
male	43. 8%
Youth Race	
African American	77.4%
White	19.9%
Other	2.8%
Caregiver Relationship to Youth	
biological parent	93.2%
other	6.8%
Type of diabetes	
Type 1	89.7%
Type 2	10.3%
Duration of diabetes (years)	4.67 (3.03)
HbA1c*	11.67 (2.53)
BMI Percentile**	74.46 (24.93)

Note: *HbA1c = blood test of 2-3 month average blood glucose level
**BMI = Body Mass Index

Table 2

Change score correlations for emotional support between diabetes outcomes

	Emotional Support	
Diabetes Outcomes	Baseline to Post Treatment	Baseline to 6 Month Follow Up
Adherence (caregiver report)	-.02	.05
Adherence (youth report)	-.10	.11
HbA1c	.04	-.04
Average Blood Glucose Tests	-.07	-.01

Note.
* p < .05. ** p < .01

Table 3
Change score correlations for parental monitoring between baseline and post treatment

	Parental Monitoring Reported by Teen					
Diabetes Outcomes	Overall	Direct Oversight	Availability of Supplies	Blood Glucose Testing	Diet	Non-adherence
Adherence (caregiver report)	-.09	-.10	-.01	.03	-.14	.039
Adherence (youth report)	.03	.06	.01	.06	-.08	.08
HbA1c	-.05	-.03	-.16	.03	.06	.07
Average Blood Glucose Tests	-.05	.02	.03	-.05	-.03	.02

	Parental Monitoring Reported by Caregiver					
	Overall	Direct Oversight	Availability of Supplies	Blood Glucose Testing	Diet	Non-adherence
Adherence (caregiver)	-.05	-.02	-.04	.06	-.11	-.01
Adherence (youth)	-.05	-.06	.06	-.03	-.12	-.07
HbA1c	.05	.05	.06	.03	.11	-.06
Average Blood Glucose Tests	-.02	-.01	-.03	-.03	-.15	.10

Note.
* p < .05. ** p < .01

Table 4

Change score correlations for parental monitoring between baseline and 6 month follow up

	Parental Monitoring Reported by Teen					
Diabetes Outcomes	Overall	Direct Oversight	Availability of Supplies	Blood Glucose Testing	Diet	Non-adherence
Adherence (caregiver report)	-.03	-.07	.21*	-.02	-.25**	-.02
Adherence (youth report)	.01	-.08	.25**	.02	-.17*	-.03
HbA1c	.02	.13	-.08	-.14	.03	.04
Average Blood Glucose Tests	-.13	-.25**	.09	-.06	-.17	.10

	Parental Monitoring Reported by Caregiver					
	Overall	Direct Oversight	Availability of Supplies	Blood Glucose Testing	Diet	Non-adherence
Adherence (caregiver)	.12	-.05	.23**	.08	-.15	-.03
Adherence (youth)	.14	.09	.15	.10	-.06	-.02
HbA1c	-.09	-.06	-.05	-.14	-.07	.001
Average Blood Glucose Tests	.10	.03	.14	.01	-.3	.10

Note.
* p < .05. ** p < .01

APPENDIX A

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.*

How often does your family:

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 at all (0)*		*Somewhat (1)*		*Very (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 at all (0)		Somewhat (1)		Very (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 at all (0)		Somewhat (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 at all (0)		Somewhat (1)		Very (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)		Somewhat (1)		Very (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 supportive (helpful) is this to you?	Not at all (0)		Somewhat (1)		Very (2)	
6. Change their own schedule to get an early start, when you give yourself morning 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)		Somewhat (1)		Very (2)	
7. Check after you've taken your insulin to make sure you have done it?	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)	
8. Let you know they understand how difficult it is to take 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)		Somewhat (1)		Very (2)	
9. 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)		Somewhat (1)		Very (2)	
10. Watch you test your blood sugars to see what the values are?	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)	
11. Test your blood sugar 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)	
12. Remind you to test your blood sugars to see what the values are?	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)	
13. Make sure you have materials needed for blood testing?	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)	
14. Let you know that they understand how hard it is to test blood sugars every day?	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)	
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)		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 to you?	Not at all (0)		Somewhat (1)		Very (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)		Somewhat (1)		Very (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 (0)		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)		Somewhat (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)		Somewhat (1)		Very (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)		Somewhat (1)		Very (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?	Not at all (0)		Somewhat (1)		Very (2)	
24. Congratulate or praise you for exercising regularly?	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)	
25. 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)		Somewhat (1)		Very (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 at all (0)		Somewhat (1)		Very (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 (0)		Somewhat (1)		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 (0)		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)		Somewhat (1)		Very (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 to you?	Not at all (0)		Somewhat (1)		Very (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)		Somewhat (1)		Very (2)	

APPENDIX B

PARENTAL MONITORING OF ADOLENCENT DIABETES CARE – PARENT

This questionnaire asks some questions about interactions that you many have with your child or others that have to do with your child's diabetes care. We would like to know how often you have done these things ***in the past MONTH.*** *The past month is the period from _____ (date) to _____ (date).*

Please answer in regard to yourself only, not what any other caregivers may do.

1. How often did you watch your child give his/her insulin?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
2. How often did you ask family members (for instance, spouse, significant other, grandparents, older siblings) whether your child had completed diabetes care?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
3. When your child ate meals outside of your home (for example, at a restaurant, at a family member's home), how often were you present?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
4. How often did your child come to you and tell you what he/she ate and how much he/she ate during the day without your asking him/her?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
5. How often did you ask your child what his/her blood glucose readings were?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
6. How often did you check your child's insulin vials to see if the expected amount had been used?	Less than once a month (1)	Monthly (2)	2-3 times a month (3)	Weekly (4)	Several times a week or more (5)
7. If your child skipped a blood glucose test, how would he/she tell you about it without your asking him/her?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
8. How often did your child's friends or friends' parents provide you with information about whether your child had completed diabetes care while spending time with them without your asking them?	Never when child was there (1)	Hardly ever when child was there (2)	Sometimes when child was there (3)	Most times when child was there (4)	Every time when child was there (5)
9. When your child took insulin or tested his/her blood glucose outside of your home (for example, at a family member's house, friend's house), how often were you present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)

10.How often did you check your child's test strips and lancets to see if the expected number had been used?	Less than once a month (1)	Monthly (2)	2-3 times a month (3)	Weekly (4)	Several times a week or more (5)
11.How often did your child come to you and tell you about the insulin he/she took during the day (e.g. when it was taken, how much was taken) without your asking him/her?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
12.How often did your child come to you and tell you about the blood glucose testing he/she did during the day (e.g. how often he/she tested, what the values were) without your asking him/her?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
13.How often did you ask school personnel whether your child had completed his/her diabetes care in school?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
14.How often did you look at the readings in your child's blood glucose meter?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
15.How often did school personnel provide you with information about whether your child had completed his/her diabetes care in school without your asking them?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
16.If your child missed an insulin dose, how often would he/she tell you about it without your asking him/her?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
17.When your child tested his/her blood glucose at home, how often were you present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
18.How often did family members (for instance, spouse, significant other, grandparents, older siblings) provide you with information about whether your child had completed his/her diabetes care without your asking them?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
19.How often did you watch your child test his/her blood glucose?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
20.How often did you ask your child if they tested his/her blood glucose?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)

21.How often did you ask your child's friends or friends' parents whether your child had completed diabetes care while spending time with them?	Never when child was there (1)	Hardly ever when child was there (2)	Sometimes when child was there (3)	Most times when child was there (4)	Every time when child was there (5)
22.How often did you ask your child what he/she had eaten?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
23.How often did you observe your child during a meal to see exactly what he/she was eating and how much he/she ate?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
24.How often did you ask your child if he/she took his/her insulin?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
25.When your child took his/her insulin at home, how often were you present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
26.If your child ate in a way that caused problems with their diabetes (for instance, skipped a meal, didn't count carbohydrates), how often would he/she tell you about it without your asking him/her?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
27.When your child ate meals at home, how often were you present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once day (5)

APPENDIX C

PARENTAL MONITORING OF ADOLESCENT DIABETES CARE – TEEN

This questionnaire asks some questions about interactions that you may have with your parent that have to do with diabetes care. We would like to know how often he/she has done these things ***in the past MONTH****. The past month is the period from _____(date) to _____(date).*

Please answer in regard to your _____ only, not what any other person may do*.*

1. How often did your caregiver watch you give your insulin?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
2. How often did your caregiver ask family members (for instance, spouse, significant other, grandparents, older siblings) whether you had completed diabetes care?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
3. When you ate meals outside of your home (for example, at a restaurant, at a family member's home), how often was your caregiver present?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
4. How often did you come to your caregiver and tell him/her what you ate and how much you ate during the day without your caregiver asking you?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
5. How often did your caregiver ask you what your blood glucose readings were?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
6. How often did your caregiver check your insulin vials to see if the expected amount had been used?	Less than once a month (1)	Monthly (2)	2-3 times a month (3)	Weekly (4)	Several times a week or more (5)
7. If you skipped a blood glucose test, how often would you tell your caregiver about it without him/her asking you?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
8. When you took insulin or tested your blood glucose outside of your home (for example, at a family member's house, friend's house), how often was your caregiver present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
9. How often did your caregiver check your test strips and lancets to see if the expected number had been used?	Less than once a month (1)	Monthly (2)	2-3 times a month (3)	Weekly (4)	Several times a week or more (5)

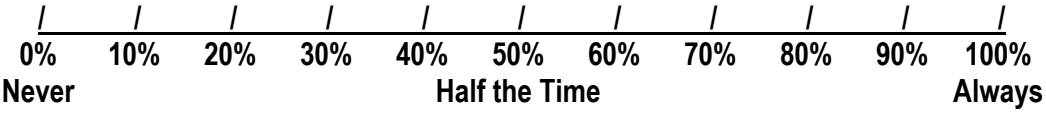
10.How often did you go to your caregiver and tell him/her about the insulin you took during the day (e.g. when it was taken, how much was taken) without your caregiver asking you?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
11.How often did you go to your caregiver and tell him/her about the blood glucose testing you did during the day (e.g. how often you tested, what the values were) without your caregiver asking you?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
12.How often did your caregiver ask school personnel whether you had completed your diabetes care in school?	Monthly or less (1)	2-3 times a month (2)	Once a week (3)	Several times a week (4)	Every day (5)
13.How often did your caregiver look at the readings in your blood glucose meter?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
14.If you missed an insulin dose, how often would you tell your caregiver about it without him/her asking you?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
15.How often did your caregiver watch you test your blood glucose?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
16.How often did your caregiver ask you if you tested your blood glucose?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
17.How often did your caregiver ask your friends or friends' parents whether you had completed diabetes care while spending time with them?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
18.How often did your caregiver ask you what you had eaten?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
19.How often did your caregiver observe you during a meal to see exactly what you were eating and how much you ate?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
20.How often did your caregiver ask you if you took your insulin?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)

21. When you took your insulin at home, how often was your caregiver present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once a day (5)
22. If you ate in a way that caused problems with your diabetes (for instance, skipped a meal, didn't count carbohydrates), how often would you tell your caregiver about it without him/her asking you?	Never (1)	Hardly ever (2)	Sometimes (3)	Most times (4)	Every time (5)
23. When you ate meals at home, how often was your caregiver present?	Less than once a week (1)	Once a week (2)	Several times a week (3)	Once a day (4)	More than once day (5)

APPENDIX D

DIABETES MANAGEMENT SCALE – CONVENTIONAL

*This questionnaire lists a number of things that people who have diabetes need to do to take care of their diabetes. We realize most kids forget to do these things some of the time; therefore, we're interested in how often _____ **actually** does these things, not how often s/he is **supposed** to do them. Remember, we don't share your answers with anyone, including the diabetes clinic staff, so please tell us what you really think s/he does. I want you to start by thinking about the past month, that is from _____ to today. Think about how often s/he does each of these things and answer using a 0% to 100% scale. 0% means s/he does this none of the time and 100% means s/he does this all of the time, s/he never misses or forgets to do it. Most people, however, fall somewhere in the middle, for example 50% means about half the time, 20% means a little bit of time, 80% means most of the time and so on.*



What percent of the time …

S. *did your teen floss his/her teeth every morning?* ..... _____%

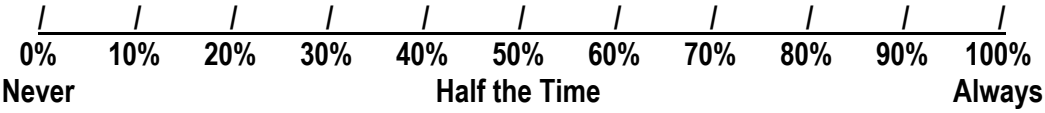
1. does your teen test his/her blood glucose the number of times s/he is supposed to? ..... _____%
2. does your teen not write down the results of his/her blood glucose tests in his/her logbook? ..... _____%
3. does your teen carry a sugar source or something to treat reactions? ..... _____%
4. does your teen get each of his/her insulin injections every day? ..... _____%
5. does your teen get the prescribed number of units of insulin in each injection? ..... _____%
6. is your teen careful in measuring his/her insulin? ..... _____%
7. does your teen give his/her insulin at about the same time every day? ..... _____%
8. does your teen not wait the right amount of time between giving his/her injection and eating? ..... _____%
9. does your teen eat foods that are not on his/her meal plan? ..... _____%
10. does your teen eat three meals a day? ..... _____%
11. does your teen eat meals at the right times during the day? ..... _____%
12. does your teen eat meals at different times every day? ..... _____%
13. does your teen eat two snacks a day? ..... _____%
14. does your teen eat snacks at the right times during the day? ..... _____%
15. does your teen eat snacks at the same time everyday? ..... _____%
16. does your teen eat without counting carbs (carbohydrates)? ..... _____%
17. does your teen give or adjust insulin without knowing what his/her blood sugar is? ..... _____%
18. does your teen exercise at least 3 days a week for at least 20 minutes at a time? ..... _____%
19. What percent of his/her diabetes care is your teen responsible for now? ..... _____%
20. In the past month, did your teen run out of test strips for his/her glucose meter? ..... Yes(1) / No(0)
21. In the past month, did your teen run out of insulin? ..... Yes(1) / No(0)
22. Out of the past 7 days, how many days did your teen skip an insulin shot? ..... _____

23. Out of the past 7 days, how many days did your teen skip blood glucose testing all day long? ..... _____

APPENDIX E

DIABETES MANAGEMENT SCALE – INTENSIVE

*This questionnaire lists a number of things that people who have diabetes need to do to take care of their diabetes. We realize most kids forget to do these things some of the time; therefore, we're interested in how often _____ **actually** does these things, not how often s/he is **supposed** to do them. Remember, we don't share your answers with anyone, including the diabetes clinic staff, so please tell us what you really think s/he does. I want you to start by thinking about the past month, that is from _____ to today. Think about how often s/he does each of these things and answer using a 0% to 100% scale. 0% means s/he does this none of the time and 100% means s/he does this all of the time, s/he never misses or forgets to do it. Most people, however, fall somewhere in the middle, for example 50% means about half the time, 20% means a little bit of time, 80% means most of the time and so on.*



What percent of the time …

S. *did your teen floss his/her teeth every morning?* ..... _____%

1. does your teen test his/her blood glucose first thing when s/he wakes up in the morning? ..... _____%
2. does your teen test his/her blood glucose before eating a meal? ..... _____%
3. does your teen not write down the results of his/her blood glucose test in his/her logbook? ..... _____%
4. does your teen carry a sugar source or something to treat reactions? ..... _____%
5. does your teen get the prescribed number of units of insulin in each bolus? ..... _____%
6. does your teen give or adjust insulin without knowing what his/her blood sugar is? ..... _____%
7. does your teen not give insulin when s/he eat carbohydrates? ..... _____%
8. does your teen eat without counting carbohydrates? ..... _____%
9. does your teen exercise at least 3 days a week for at least 20 minutes at a time? ..... _____%
10. What percent of his/her diabetes care is your teen responsible for now? ..... _____%
11. In the past month, did your teen run out of test strips for his/her glucose meter? ..... Yes(1) / No(0)
12. In the past month, did your teen run out of strips to test for ketones? ..... Yes(1) / No(0)
13. In the past month, did your teen run out of insulin? ..... Yes(1) / No(0)
14. Out of the past 7 days, on how many days did your teen skip an insulin injection/bolus? ..... _____
15. Out of the past 7 days, how many days did your teen skip blood glucose testing all day long? ..... _____

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ABSTRACT

A WARM WATCHFUL EYE: PARENTAL EMOTIONAL SUPPORT AND MONITORING IN MULTISYSTEM THERAPY FOR YOUTH WITH DIABETES

by

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Advisor: Dr. Annmarie Cano

Major: Clinical Psychology

Degree: Master of Arts

The purpose of this study was to examine the extent to which changes in parenting behaviors, in particular monitoring diabetes care completion and providing emotional support to the youth, improve health care status within participants in a Multisystemic psychotherapeutic intervention (MST). RM-ANOVAs were used to determine the relationship of parental involvement in the treatment and telephone support group over time. Change score correlations were used to examine changes in parental involvement relationship to changes in diabetes care behaviors. All participants in the study increased in parental monitoring over time, with no differences between the MST group and the telephone support group. Changes in types of parental monitoring were related to changes in adherence. Emotional support showed no change and was not related to diabetes outcomes. This research suggests parental involvement alone does not change diabetes behaviors but may be an important contributor and should be studied further to understand how to assist youth with diabetes.

AUTOBIOGRAPHICAL STATEMENT

Dana May was born outside of Madison, Wisconsin. She showed an early interest in working with youth and health and planned to pursue a career in pediatric medicine. Her first year of undergraduate university, she developed an interested for psychology in addition to biological sciences. She continued to seek opportunities that merged her two interest through research, coursework and profession development at the University of Wisconsin-Madison. During her fourth year of undergraduate university, her close graduate student research mentor took a clinical placement in health psychology. Although the mentor did not care of this field, her stories of her experiences sparked Dana's interest in the field. Upon graduation, Dana explored the clinical aspects of psychology by working in an acute impatient psychology hospital in Madison associated with the University of Wisconsin-Madison. The hospital cared for children and adolescents with a wide range of acute psychological distress, including youth with chronic medical conditions. After working for two years, she was confident that she had found her passion: helping youth and their families cope with chronic illness. Dana applied to Clinical Psychology programs that allowed her to blend her interest in youth and health in a science-practitioner model of learning. She feels grateful to have found a amazing fit at Wayne State University and working with a supportive advisor, Dr. Annmarie Cano, pursuing her interest pediatric psychology. In her free time, Dana can be found working with livestock on her family's farm, traveling, and enjoying various outdoors activities.