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Pepperdine University
Graduate School of Education and Psychology

PSYCHOLOGICAL CARE FOR TYPE 1 DIABETIC ADOLESCENTS: DESIGNING A NEW
MODEL OF INTEGRATED CARE

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by

Stephanie R. Young

March, 2014

Stephanie Woo, Ph.D. – Dissertation Chairperson

This clinical dissertation, written by

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under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

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DEDICATION

To all of those around the world living with insulin-dependent diabetes, I dedicate this work to you. May every contribution of research, from the simplest of experiments to the most groundbreaking of discoveries, help to relieve the burden of this disease for you.

And to the determined scientists who dedicate their lives to unraveling the mysteries of this complicated disease, may you continue to enrich humanity with your passion and perseverance.

ACKNOWLEDGEMENTS

I have completed this dissertation—and my doctoral studies—because of the contributions of many individuals who have played a defining role in my education. Isaac Newton famously proclaimed, “If I have seen further it is by standing on the shoulders of giants.” In my doctoral education, I have been privileged to have “seen further” by building on the wisdom and experience of many dedicated faculty mentors, admired peers, and family.

First, I would like to express my most sincere gratitude to Dr. Stephanie Woo, whom I have been exceptionally lucky to learn from for the past five years. Dr. Woo is a remarkably talented psychologist, researcher, and educator who has taught me powerful lessons in each of these capacities. She has left an imprint on me on how to think in a creative fashion, focus my efforts, write simply yet persuasively, and navigate unexpected challenges. I thank her for making this process of developing and writing this dissertation such a stimulating and rewarding one. I graduate from this university as the beneficiary of exemplary mentorship thanks to her.

I wholeheartedly thank my dissertation committee members, Dr. Robert deMayo and Dr. Sepida Sazgar, for their many contributions throughout each phase of this dissertation. They raised important questions and offered their astute observations that led to critical developments in the program I proposed. Beyond the many clinical and research pearls I have learned from Dr. deMayo, I have been taught what it means to be a courageous leader and advocate from him. I thank Dr. deMayo for being a powerful voice for us students and all of the individuals whom we strive to serve in this field. Dr. Sazgar taught me many of my first lessons in psychotherapy early on, and she has been an incredible source of academic nourishment that has sustained and inspired me since. Her drive for understanding diverse populations of patients, particularly those

with complex medical diagnoses, is commendable, and I feel privileged to have learned from her. I could not have asked for more thoughtful or wise committee members.

There are many friends to whom I owe huge gratitude. Each day during this journey of becoming clinical psychologists, I have been astounded by the thoughtful minds and the extraordinarily generous and open hearts each of them have. Studying and working together has been one of the most gratifying experiences of my life. Not surprisingly, some of the most powerful lessons I learned along the way are from them.

My family has meant the world to me in this process. My late grandparents, Gerard and Ann Clarke, and James and Mildred Young, were each teachers in their lifetimes. I have no doubt that their devotion to education had an important impact on what I have striven for in my own career. My aunts and uncles have continually imparted upon me fundamental life lessons, and I have benefited from their vast knowledge and encouragement during this process. I owe special thanks to my uncle and aunt, Steven and Catherine Clarke, who have been an unyielding source of support. They have always carried forth the spirit of scientific inquiry in their lives as researchers, which has also motivated me deeply.

My brother, Brian Young, has some of the most extraordinary insights about the natural world and the human experience than anyone I have ever encountered. Every day, I am appreciative of his empowering me to stretch my mind to recognize novel connections among disparate disciplines of knowledge. He has been steadfast in his support of my studies. He has taken a sincere interest in my daily experiences over the course of this training period, and is quick to generously share his pride in my endeavors. He continually reminds me of the manifold virtues of the work of clinical psychology, and for this I am extremely grateful.

My sister, Madeline Young, is the sharpest, most enthusiastic, and loving soul. I derive tremendous strength from her. Throughout all of my schooling, her positivity and open-mindedness have invigorated me. She has broadened my perspectives and provided a sense of balance; she has been the light that has made the most difficult hour my “finest hour.” I thank her for always encouraging me to shape my work into that which is the most meaningful to me. She is a terrific example of one who has used her education to make the world a better place; my heartiest appreciation for her model of how to do this in a courageous way.

My husband, Neil Bajpayee, has cheered me on throughout the happiest of moments and has held my hand tightly during the most trying of times. One of the most curious minds I know, Neil unreservedly seeks to answer questions he does not yet understand and inspires me to think anew about humankind. His quest for knowledge, done in a most humble fashion, is admirable. I hope that in our lifetimes, we will be able to learn of new advances in the treatment of type 1 diabetes. I thank him for serving as an inspiration for the focus of this dissertation. I am eternally grateful for having found an everlasting love in Neil.

And finally, my parents, Stephen and Lorraine Young, have been unwavering in their support of my intellectual journeys. They serve as the ultimate model of a lifelong commitment to learning. From the days of my earliest schooling, they have instilled within me that I have a responsibility to learn, discover, and grow throughout my life. They told me that it would never come easy, and I would have to actively strive to acquire an education that would enable me to contribute in a purposeful way to our society. They have made immense sacrifices for me to pursue all my educational endeavors—every single step of the way. I thank them deeply for encouraging me to have integrity, courage, and faith in myself. They inspire me to always strive for the best of the best. I dedicate my dissertation and my doctoral degree to both of them.

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ABSTRACT

Diabetes mellitus is among the most common chronic diseases in children and adolescents, affecting approximately 1 in 400 children. Type 1 diabetes mellitus (T1DM) requires a complex and arduous daily management regimen. The disease can present dramatic changes in daily life, placing a significant psychological burden on the child. Behavioral and psychological factors can significantly influence the course and progression of T1DM. These interactions are bidirectional—metabolic and biological fluctuations produce alterations in emotions and behaviors, and psychological functioning predicts glycemic control and other medical outcomes.

A particularly high-risk group within the T1DM patient population is adolescents. Given the critical biological, cognitive, emotional, and social changes that occur during adolescence, glycemic control typically diminishes. T1DM can also increase the adolescent's risk for psychiatric illness and can contribute to decreased self-esteem, conflict with family, peer difficulties, and poor coping with illness demands.

To address this need, the dissertation sought to design a program that appropriately addresses the psychological care of T1DM adolescents, to format the program for integration into the tertiary medical clinic setting, and to design an evaluation tool that can be used to evaluate the program for clinical utility in future studies. Although prior studies have identified specific components of interventions (e.g., cognitive-behavioral therapy, coping skills training, stress management, motivational interviewing) that have been shown to be generally effective in improving psychological outcomes, never before have each of the tested individual interventions been integrated to create a comprehensive, multi-level program for this population. In addition, no comprehensive program to the investigator's knowledge has been specifically designed for

implementation in an integrated care context, where patients are treated by an interdisciplinary team of professionals.

Empirical findings in the literature were systematically evaluated to identify the most efficacious programmatic elements. Then, applying the recommendations discussed in the health services delivery literature, the program content was designed for delivery of services within the medical clinic in the most feasible and effective way. Finally, program evaluation was discussed, and an evaluation measure was developed for use in future pilot studies investigating the efficacy and utility of this program.

Chapter 1: Introduction and Statement of the Problem

This dissertation proposes to create a comprehensive program that is specifically tailored to address the psychological needs of children and adolescents with insulin-dependent diabetes mellitus (Type 1 diabetes mellitus, or T1DM). The program will be designed for integration into the medical setting, primarily the outpatient pediatric endocrinology clinic, for use by psychologists who work as part of multi-disciplinary teams to treat children with chronic diseases such as T1DM. Integration of mental and physical health services is critical in this population, as is often said that the psychological demands associated with the management of diabetes are as significant and extensive as the medical ones. Therefore, a program that is borne out of a patient-centered and holistic framework, which emphasizes the importance of treating all aspects of an individual patient, has the potential to most effectively optimize outcomes. The program targets pediatric patients given the strong evidence for the importance of early education and intervention on the development of practices that are crucial for coping with the demands of the taxing lifelong illness.

Importantly, the program's delivery of care model is responsive to recent global trends and paradigm shifts in the provision of health services. The integration of mental and behavioral health services into the medical setting—"integrated care"—is a relatively new model built to address major recent structural changes in health care reform. Specifically, with the passage of the Patient Protection and Affordable Care Act in 2010, among other shifts in the access and delivery of health care, an emphasis on integrated mental and physical health care was introduced. In response to such legislation, in 2012, the American Psychological Association (APA) initiated a strategic plan to promote the role of psychology within the health care enterprise to stimulate more holistic approaches to health. The 2012 APA President focused

efforts to advocate for the importance of psychologists and psychological care within medical specialty and primary care clinics (e.g., Johnson, 2012). For a chronic illness such as diabetes, integrated care would ideally enhance health outcomes, expand access to appropriate treatment, increase convenience and compliance for patients and families, and reduce stigma associated with psychological services.

This program proposes a comprehensive, integrated care model to provide a full spectrum of psychological services for T1DM adolescents, which expands the literature base in two central ways. First, despite the recent progress made in the development and delivery of integrated care across the nation, to my knowledge, no integrated program currently exists to target the psychological sequelae of diabetes for T1DM patients in specialty medical clinics. Therefore, the program proposes a new model of care adapted to the pediatric endocrinology clinic, where most T1DM diabetics receive routine services. It delineates the roles and functions of the psychologists (and other professionals), the collaborative processes, and the clinical care strategies in detail. In effect, it proposes principles and guidelines specifically for the psychologist's role in interdisciplinary care to facilitate patient-centered diabetes care.

Secondly, the program is built entirely upon empirically-validated psychological intervention studies. Many of the existing intervention studies have documented significant improvements in biological and psychological outcomes resulting from particular effective components or aspects of a given treatment. To date, however, the studies have not attempted to bridge existing successful interventions together to create a comprehensive, multi-level program for T1DM adolescents. In other words, there have not been large-scale clinical studies incorporating and synthesizing the specific interventions shown to have the greatest effect sizes. This dissertation identifies the interventions most successful in treating the multiple tiers of the

patient's psychological and medical care. Then, the most efficacious interventions and components of interventions are combined in a systematic manner to build a multi-faceted program for the target population.

The program will be rooted in psychological and public health theory as well as in empirical science. Significant consideration of the recommendations for psychological care delivery highlighted by the recent health services literature will be given in the program's development. In addition to the development of the program, an evaluation tool will be included that can be utilized in future studies. The evaluation measure is designed to be used prior to implementation to determine the potential efficacy and feasibility of the program in a particular setting. Specifically, the evaluation measure seeks to: (a) identify the specific strengths and limitations of the clinical and scientific aspects of the program's selected diabetes interventions; (b) identify the general strengths and limitations of the model of integrating psychological care into a tertiary medical setting; and (c) measure the professionals' attitudes and beliefs about integrated psychological care as a whole. This measure may help to facilitate analysis of the program's potential clinical effectiveness for the T1DM adolescents as well as the potential feasibility of a new model of care as a function of provider attitudes and beliefs about integrated care. Ultimately, the data from the evaluation may also yield insight into the degree to which professionals would be open to, utilize, and find clinical value in the program and its care delivery model. Additionally, it would allow for a theoretical and empirical model upon which to refine, build, and measure the cumulative effects of the selected interventions in future studies.

The following literature review will survey key relevant background literature to inform readers of the scope and phenomenology of T1DM and the psychological sequelae that are frequently experienced by youth affected by this illness. The review will involve a discussion of

the current psychological interventions for T1DM, and will provide an extensive discussion of the cognitive-behavioral model of diabetes and cognitive-behavioral treatment approaches, which have been shown to be most efficacious in this population. The review will conclude with a discussion of integrated care, particularly in the context of pediatric chronic disease, and will highlight the challenges that have been identified in integrating behavioral health into the routine medical care of children and adolescents with this illness.

Statement of the Problem

Type 1 diabetes mellitus (T1DM), also known as insulin-dependent diabetes or juvenile-onset diabetes, is estimated to affect between one million and three million people living in the United States (Dall et al., 2009; Juvenile Diabetes Research Foundation International [JDRF], 2011); this group accounts for approximately five to ten percent of the approximately 26 million total cases of diabetes (Centers for Disease Control and Prevention [CDC], 2011). Diabetes (type 1 or type 2) is among the most common chronic diseases in children and adolescents, and according to the CDC, affects about 215,000 individuals below the age of twenty in the United States or about one in 400 children and adolescents (CDC, 2011). Approximately 15,000 American children and adolescents are diagnosed with T1DM each year (CDC, 2011) representing an incidence of 19 children per 100,000 annually (Dabelea et al., 2007). Importantly, the incidence of T1DM among youth worldwide is increasing rapidly at a rate of approximately three percent per year (Bessaoud et al., 2006; International Diabetes Federation [IDF], 2009), which represents a pressing global public health problem, especially among the youngest children. One international epidemiological study suggests that by 2020, the number of T1DM cases in children younger than five years will double, and the prevalence of cases of individuals below 15 years will increase by 70% (Patterson et al., 2009). T1DM also imposes

serious economic costs (Milton, Holland, & Whitehead, 2006). A recent study suggests that medical expenditures attributable to T1DM patients fall between 5.9 and 7.9 billion dollars annually in the United States, with an additional 7.5 billion dollars estimated to be incurred due to lost income per year (Tao, Pietropaolo, Atkinson, Schatz, & Taylor, 2010).

Typically diagnosed in children and young adults, T1DM is characterized by failure of pancreatic beta cells to produce insulin, the peptide hormone that regulates glucose metabolism (for a review, see American Diabetes Association [ADA], 2012a). This is in contrast to type 2 diabetes mellitus, the more prevalent form of the disease, which occurs due to insulin resistance. Type 2 diabetes is usually diagnosed in middle to late adulthood, and can be managed with medication (rather than insulin treatment). T1DM is an autoimmune disorder wherein the body's immune system attacks and destroys the pancreatic cells, although genetic and environmental factors have also been implicated in its development (thus, there remains some lack of clarity regarding etiology). In a healthy individual, the pancreas secretes a basal level of insulin; when food is ingested, the pancreas is stimulated to release insulin. After a meal, glucose levels in the bloodstream rise, and insulin is secreted to allow uptake of blood glucose into the tissues of the body, where it can be utilized for energy. In the absence of insulin, glucose uptake from the bloodstream is deficient, and hyperglycemia occurs (the body's cells essentially starve). Type 1 diabetics depend upon exogenous insulin replacement for survival, either through wearing an insulin pump or through multiple direct injections of insulin daily. The amount of insulin administered requires knowledge of blood glucose levels because these change throughout the day; thus, the diabetic must prick his or her finger multiple times daily and test the blood using a glucose meter in order to avoid hypoglycemia or hyperglycemia. The goal of the T1DM

patient's treatment is to maintain control of glucose levels within the normal range of 70–130 mg/dL (American Diabetes Association, 2012b).

Current insulin therapy has transformed T1DM from a once fatal disease (in the early twentieth century) to a chronic illness. However, even with daily management of blood glucose levels, there are both short- and long-term complications that can arise (for a review, see Nathan et al., 2005; Shamoon et al., 1993; Ziegler et al., 2011). In the short term, excessively high blood glucose levels lead to hyperglycemia, which can result in diabetic ketoacidosis (DKA), a life-threatening condition, or a diabetic coma. Short-term effects of unrecognized hypoglycemia, excessively low blood glucose levels, include loss of consciousness, seizures, or even death. Over time, persistent or untreated hyperglycemia produces serious organ damage, particularly in the nerves and the microvasculature of the eyes, kidneys, and heart, resulting in retinopathy, neuropathy, and cardiac events (Nathan et al., 2009). Thus, it is crucial that the type 1 diabetic consistently attend to the management of the disease. Maintaining tight glycemic control may delay the onset of and/or minimize the impact of complications, according to a nationwide prospective study that took place in the 1980s, the Diabetes Control and Complications Trial (Shamoon et al., 1993). Unfortunately, there is evidence that even with glucose levels tightly regulated over time, type 1 diabetics have a shorter life expectancy and typically die of renal failure or cardiac disease (Nathan et al., 2005; Nathan et al., 2009). Evidence also suggests diabetes is a risk factor for cognitive decline (Genuth et al., 2007). There is tremendous value, however, in understanding optimal management of diabetes for these patients in order to increase their life expectancy, health outcomes, and quality of life. The many demands of T1DM influence and are impacted by multiple psychological processes, which are reviewed below.

Chapter 2: Review of the Literature

Specific Considerations and Challenges in the Psychological Care of Pediatric T1DM

Patients

According to the International Society for Pediatric and Adolescent Diabetes (2000), “psychosocial factors are the most important influences affecting the care and management of diabetes” (Psychological, social and financial issues section, para.1). This chronic illness requires a complex and oftentimes arduous daily regimen and can present dramatic changes in lifestyle, placing a significant psychological burden on the child. Fortunately, there has been increased recognition of the critical role of behavioral, lifestyle, and psychological factors that influence the course and progression of T1DM. These interactions are bidirectional—metabolic and biological fluctuations produce alterations in emotions and behaviors, and psychological functioning predicts metabolic control and diabetes outcomes. Several of the major psychological predictors of T1DM health outcomes are reviewed here.

Effects of stress on adherence and glycemic control in T1DM. Psychological stress has received a tremendous amount of attention over the past three decades in terms of its relationship to specific biological processes implicated in chronic disease (such as the stress response, endocrine functioning, and immunity). The role of stress on disease outcomes in children and adolescents are no exception (see a review by Nassau, Tien, & Fritz, 2008). T1DM youth experience stress both acutely (e.g., experiencing an unpredicted hypoglycemic episode) and chronically (e.g., recurrent conflict in the family, low socioeconomic status) (La Greca, 1992). In T1DM, both types of stress create disturbances in a child’s glucose metabolism, both directly and indirectly.

Indirectly, stress disrupts management routines, which can negatively impact adherence to the treatment regimen, and thereby glycemic control (Peyrot, McMurry, & Kruger, 1999). Johnson (1995) posits that adherence is the central node in a model of multiple psychological predictors of glycemic control, with other variables (e.g., knowledge about the disease, adjustment to the diagnosis, coping skills, family adaptation to the illness, peer support, and the relationship with the health care provider) moderating this relationship. Adherence to treatment in chronic disease is generally considered to be strongly predictive of medical outcomes. There is a vast literature concerning compliance to treatment, but Kakleas, Kandyla, Karayianni, and Karavanaki (2009) summarize it briefly: generally, a lack of disease-related knowledge within the first several years post-diagnosis influences adherence; later, compliance depends upon parental support of management and avoiding unhealthy patterns of diet and behavior. In diabetes, the relationship between adherence and glycemic control is complicated and likely bi-directional in that poor compliance may be triggered by deteriorating glycemic control, and vice versa (Kakleas et al., 2009). Adherence may not necessarily be the mediator (Hanson & Pichert, 1986), but generally it is observed that experiencing significant stressors secondary to the demanding treatment regimen is strongly correlated with poorer metabolic control (and related medical outcomes). For instance, in adolescent patients, stress specifically pertaining to perceptions of diabetes-related negative social evaluation has been associated with lowered glycemic control (Hains et al., 2007).

Broadly, these stressors that have an indirect effect on physiology include having to restrict the diet and deprive oneself of preferred foods, needing to closely monitor blood glucose several times daily and immediately respond to unpredictable fluctuations, having persistent worry about inaccurately estimating necessary amounts of insulin (and fearing the potential of

ensuing hypoglycemia), and experiencing conflict with caregivers (both personal and professional) over management behaviors (Rubin & Peyrot, 1992). The task of monitoring and responding to fluctuating blood glucose levels is further complicated by the child's involvement in activities that may quickly alter glucose levels, such as sports. Physical activity contributes to differential glucose metabolism, the extent of which may be entirely unpredictable for a child, especially with the varying activities and duration of time spent on a specific activity. Similarly, social activities can be stressful in that they often necessitate departing from one's dietary routine (e.g., selecting different foods and beverages, eating at irregular times of the day), which can alter blood glucose status unpredictably.

There is stronger empirical evidence for the direct effects of stress on glycemic control (e.g., Hanson, Henggeler, & Burghen, 1987). Although very complex physiological processes occur in response to stress, generally speaking, stress activates two primary biological stress-responsive pathways, which result in profound effects on glucose regulation and metabolism. One is the sympathetic-adrenal-medullary (SAM) system, which secretes catecholamines (e.g., epinephrine and norepinephrine). In terms of glucose metabolism, epinephrine binds to receptors in the liver to produce glycogenolysis (glucose production), and also promotes lipolysis, which also increases glucose levels. The other stress-responsive mechanism is the hypothalamus-pituitary-adrenal (HPA) axis, the end product of which is cortisol, a steroid hormone that stimulates the production of glucose by the liver and renders lipid and muscle cells unresponsive to insulin. Thus, over time, cortisol causes decreased sensitivity to insulin, requiring greater levels of exogenous insulin replacement by the T1DM patient.

In experimental studies, it has been shown that compared to healthy controls, T1DM adults experience more prolonged glucose elevations in response to infusion of epinephrine and

cortisol (Berk et al., 1985; Shamoon, Hendler, & Sherwin, 1981). In contrast, in an experimental study with T1DM adolescents, Delamater et al. (1988) found that in response to a laboratory stressor, no significant metabolic or hormonal changes were observed, despite reports of increased perceived stress. It may be that chronic stress may produce greater effects than experimentally-manipulated acute stress. In correlational studies, a significant association was found between stressful life events over the previous three months and glycosolated hemoglobin (also known as hemoglobin A_{1c}, a biomarker of the average plasma glucose concentration over a long period of time) in older adolescents (Chase & Jackson, 1981). Additionally, a study conducted by Hanson and Pichert (1986) found a significant relationship between daily perceived stress and mean plasma glucose levels among youth attending a diabetes camp.

Overall, there is great methodological variability across studies of glycemic control and stress in pediatric populations (e.g., type of study, measures used, etc.), which limit firm conclusions about the impact of stress on metabolic control. Although it is clear that stress is linked to glycemic control in T1DM children, the mechanisms underlying this relationship remain uncertain. There may be certain diabetic patients who consistently respond to stress with increases in blood glucose, and others that experience decreased glucose levels. Thus, it is important to examine the environmental, psychosocial, and cognitive moderators of stress, including coping style. In many chronic illnesses, the degree of influence that stress exerts is thought to depend significantly on the patient's appraisal of the stressor itself and his or her perception of the capacity to cope with the stressor (Lazarus & Folkman, 1984). Therefore, it is useful to evaluate the effect of stress alongside specific coping styles; coping is reviewed next.

Effects of coping style on T1DM. Studies examining the relationship between styles of coping in diabetic children have found that children who utilize avoidance as a coping

mechanism have poorer glycemic control (Grey, Lipman, Cameron, & Thurber, 1997). The Ways of Coping Checklist, a measure of coping styles and patterns developed by Folkman and Lazarus (1980) has been used in several observational studies in youth with T1DM. In a study using this measure, a significant association was observed between poor metabolic control and the avoidance/help-seeking and the “wishful thinking” coping styles (Delamater, Kurtz, Bubb, White, & Santiago, 1987). The authors noted that children with poor control often use a more inhibited pattern of coping and those with better control used active coping styles. A follow-up study demonstrated that youth who endorsed self-blame in response to diabetes-related stress were found to have poorer glycemic control and the learned helplessness style of coping was also linked to poor control (Kuttner, Delamater, & Santiago, 1990). Additionally, one study showed that maladaptive coping mechanisms were linked to decreased adherence to the diabetic regimen, which may indirectly reduce metabolic control (Grossman, Brink, & Hauser, 1987). On the other hand, children and adolescents who have better glycemic control tend to engage in active coping and have a higher degree of self-efficacy (Delamater, 2009).

Health beliefs. Whether a child adheres to adaptive and healthy behaviors depends on several factors involving perception of the threat that the illness poses, potential benefits and costs of managing the illness, and cues to engage in treatment behaviors, according to the Health Belief Model (developed by Janz & Becker, 1984). In a study testing the predictive utility of this model in minority T1DM adolescents (Patino, Sanchez, Eidson, & Delamater, 2005), the authors questioned whether perception of illness-related risk determined whether or not they would engage in healthy and protective behaviors, using self-report measures such as the Diabetes Health Beliefs Questionnaire, the Diabetes-Related Health Problems, and Self-Care Inventory as well as the biologic measure HbA_{1c}. They suggest that while youth may perceive greater threat

for short-term complications such as hypoglycemia and hyperglycemia, the youth perceive lesser severity and susceptibility related to long-term consequences (e.g., kidney disease, neuropathy) due to a lack of cognitive maturity. The youth generally believed they themselves had less of a chance of experiencing long-term complications compared to others. Furthermore, they were unable to articulate long-term consequences of poor glycemic control. Moreover, an appreciable percentage of the adolescents also did not adhere strongly to insulin, diet, and exercise recommendations. Interestingly, the authors uncovered gender differences across exercise adherence; females had a lower level of adherence. The authors speculated that this gender difference was observed due to males generally spending more time engaging in moderate or strenuous exercise compared to females (which is consistent with literature of exercise patterns in youth).

Certainly, developmental factors are important to consider in determining how T1DM youth make management decisions and take various risks. Given that many youth do not consider risks to be as relevant to themselves, interventions that focus on risk perception for short-term complications to increase current adherence and also foster increased knowledge and awareness about long-term complications would be important.

Child adjustment to T1DM. Children diagnosed with chronic diseases have an increased predisposition for psychological morbidity, generally speaking (Lavigne & Faierroutman, 1992). In the aftermath of the T1DM diagnosis, it is not uncommon for the child to experience sadness, social withdrawal, and anxiety (Northam, Matthews, Anderson, Cameron, & Werther, 2005). During the initial period of time post-diagnosis, children are at greater risk for adjustment problems (Grey, Cameron, Lipman, & Thurber, 1995), and if adjustment difficulties do occur, they are much more likely to be long-lasting (Kovacs, Ho, & Pollock,

1995). In fact, according to Kovacs et al. (1985), about one-third of children meet criteria for an adjustment disorder within three months of diagnosis. Other adjustment-related problems include passivity and unhealthy reliance on the parents for managing the treatment regimen (Evans & Hughes, 1987). It has also been reported that in adolescents, the diagnosis engenders feelings of rebellion, leading to non-adherence.

Interestingly, however, despite these problems initially, many studies indicate that many T1DM children are relatively resilient and many appear to adjust well psychologically over time (e.g., Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007). Importantly, adjustment problems that persist do pose significantly higher risk for poor diabetes management and glycemic control in adulthood (Bryden et al., 2001). For instance, the risk for depression related to adjustment problems increases substantially within two years of T1DM diagnosis (Grey et al., 1995). One longitudinal study suggested that the lifetime prevalence rate of psychiatric disorders in T1DM youth was 37% (Northam et al., 2005).

Psychiatric diagnoses in the T1DM population. Psychiatric disorders are commonly seen in the T1DM population (Blanz, Renschriemann, Fritzsigmund, & Schmidt, 1993; Drotar, 2006). The most prevalent diagnoses include depression, anxiety, and eating disorders, and externalizing/behavioral disorders are also represented in this population, to a smaller degree (Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003). Depression and eating disorders are most common and are reviewed in detail below. Anxiety disorder rates have been found to be approximately 10-20% of the T1DM population, with disruptive behavioral disorders occurring at about the same frequency (Leonard, Jang, Savik, Plumbo, & Christensen, 2002). Some evidence also suggests that diabetic adolescents are at increased risk for substance abuse, given a strong desire for acceptance by peers (Shaw, McClure, Kerr, Lawton, & Smith, 2009). Most

frequently, substances used by adolescents in this population are cigarettes and alcohol, but studies have reported a very wide variation in usage rates and substance disorders are not considered to be a significant problem for T1DM youth. Importantly, up to 60% of youth with a psychiatric diagnosis meet criteria for another diagnosis (Northam et al., 2005).

There is a degree of debate in the literature, however, about diabetes posing a specific risk for the development of a psychiatric disorder. For instance, Johnson (1995) reports in her review that the stress and emotional changes that occur in T1DM, while significant and disruptive to daily life, do not consistently result in diagnosable psychopathology in the preponderance of these children. Indeed, Bryden et al. (2001) indicated that psychiatric morbidity in youth with T1DM is not significantly different from the general population. However, the duration of time over which a psychiatric illness can develop is important to consider. Kovacs, Obrosky, Goldston, and Drash (1997) found that over one-third of youth develop a psychiatric disorder within the first ten years after diagnosis. Another prospective study determined that 37% of adolescents studied meet criteria for a DSM-IV psychiatric disorder over the lifetime (a rate two to three times the community rate) (Bird, 1996). Interestingly, if psychiatric morbidity develops, females are more likely than males to be diagnosed (Northam et al., 2005).

When psychiatric disorders co-exist with diabetes, there are significant negative impacts on the course of the disease. First, psychiatric disorders are associated with a greater frequency of hypoglycemia and hyperglycemia as well as DKA (Rubin & Peyrot, 1992). Another study found that over half of T1DM children with a co-morbid psychiatric illness displayed a significant level of non-adherence to their regimen; in contrast, only 17% of the children without a psychiatric diagnosis also had adherence failures (Kovacs, Goldston, Obrosky, & Iyengar,

1992). Psychiatric diagnoses were present in half of those with a history of chronic poor metabolic control compared to one quarter of well-controlled participants (Northam et al., 2005).

Depression. Depression is one central psychiatric morbidity in adolescent T1DM: major depressive disorder (MDD) and dysthymic disorder are the most prevalent diagnoses in this population. Research shows that depression exists in about 25% of T1DM adolescents (Hood et al., 2006). In one study, ten years after diagnosis, one-fourth of T1DM individuals had experienced one episode of major depression in several studies (Goldston et al., 1997; Kovacs, Obrosky, Goldston, & Drash, 1997). Another study indicated that the probability of MDD or dysthymia was 27.5% by ten years post-diagnosis (Northam et al., 2005). In a longitudinal follow-up study of youth with MDD and T1DM, one-third had not recovered from their first episode of MDD by one year after onset, and less than 40% received treatment for the episode (Kovacs et al., 1997). Female adolescents were found to be at nine times greater risk for recurrent depression compared to males (Kovacs et al., 1997).

Depression in T1DM children is often precipitated by feelings of loss of motivation, anhedonia, and hopelessness related to managing the diabetes. The presence of family conflict can reduce feelings of support within youth, increasing sadness and stress; peer relationships and peer pressure within the context of forming an identity also influence risk for depression (Grey, Whittemore, & Tamborlane, 2002). Symptoms of depression can also overlap with symptoms of diabetes, including weight loss, fatigue, and problems with memory, so depression may be under-diagnosed in this group.

Depression is a particularly risky psychiatric co-morbidity with T1DM, as depression is linked to diabetic-related hospitalizations and poor glycemic control (Hassan, Loar, Anderson, & Heptulla, 2006; Hood et al., 2006; Stewart, Rao, Emslie, Klein, & White, 2005). Poor

management and control may relate to decreased self-care and treatment compliance, which may be associated with feelings of apathy. Internalizing symptoms were associated with increased health services utilization, possibly due to the similarity between somatic symptoms of depression and diabetes symptoms (Cote et al., 2003). Finally, suicidal ideation among T1DM adolescents was found to be associated with significant non-adherence to the medical regimen (Goldston et al., 1997). One study suggested that a tenfold increase in suicidal ideation is present among T1DM adolescents (Kokkonen, Lautala, & Salmela, 1997). However, reports about the risk for suicidal ideation vary in the literature; some state that suicidal ideation and attempts are on par with rates within the general population, and many studies point out that very few T1DM adolescents attempt suicide (Goldston et al., 1997).

Eating disorders. Eating disorders represent common psychiatric diagnoses in the T1DM population. Prevalence rates among T1DM adolescents range from 8% to 30% (Kakleas et al., 2009), with much higher rates among females than males. This prevalence is much higher than in the non-diabetic adolescent population (1-4% prevalence rate). Studies vary in terms of specific prevalence rates, but typically, prevalence rates are 10-20% among T1DM adolescent girls (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007; Steel, Young, Lloyd, & Macintyre, 1989). Disturbed eating patterns are observed more frequently in older adolescents (Colton et al., 2007). Specifically, bulimia nervosa and binge eating disorder are the most prevalent (anorexia nervosa is significantly less common). An additional 14% are thought to have sub-threshold eating disorders (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000). Examples of disordered eating among T1DM adolescents include dieting, binge-eating, laxative use, self-induced vomiting, engaging in excessive exercise, and manipulating insulin treatment for weight control. Eating disorders can be especially dangerous in that they are associated with increased diabetic

ketoacidosis (DKA) episodes, hypoglycemic episodes (due to not consuming meals regularly), and longer-term complications secondary to poor glycemic control (e.g., neuropathy, retinopathy, and nephropathy) (Franzese et al., 2002).

It has been suggested that eating disorders are relatively common within T1DM patients primarily because of the focus on the strict diet that the treatment requires (Antisdel & Chrisler, 2000), particularly with regard to control of certain foods and to issues related to autonomy in diet decisions. Additionally, insulin treatment results in weight gain, which is an unappealing side effect of treatment for some adolescents, prompting reduction of the prescribed dosage of insulin or omission of the injection altogether (Takii et al., 2002). One support suggested that approximately 15-40% of adolescents use or have used insulin manipulation (Peveler et al., 2005). Insulin omission behaviors can also result in hyperglycemia (Peveler, Fairburn, Boller, & Dunger, 1992).

In terms of risk factors for eating disorders, adolescents with T1DM have been shown to have lower self-esteem compared to their healthy counterparts (Wolman, Resnick, Harris, & Blum, 1994). T1DM also predisposes adolescents to higher body mass indexes, which is related to body dissatisfaction and low self-worth; both of these variables predict the onset of unhealthy eating behaviors (Colton et al., 2007). The presence of other psychiatric disorders and eating disorders in parents, especially the mother, also are risk factors for disordered diet attitudes and behaviors (Kakleas et al., 2009). From a demographic standpoint, females (aged 13-14) and males (above age 16) are at highest risk, likely due to puberty-induced hormonal and psychosocial changes (Rosen, Silberg, & Gross, 1988).

Family influences on T1DM. In the aftermath of the T1DM diagnosis, often the family experiences a sense of “loss” of a perfectly healthy child (Northam, Todd, & Cameron, 2006),

which may precipitate a psychological “crisis.” Parents and family members struggle to find the balance between being passive managers of the disease and excessively involved in care. The parents’ own frustration and psychological responses to the illness has particular impact on patterns of communication. Despite the specific reactions and responses of the family members, diabetes is bound to affect the entire family. Diabetes is often considered a family enterprise in that the disease demands lifestyle changes that often extend into the whole household.

Research findings indicate that family cohesion, level of supportiveness, warmth, nurturing, amount of collaborative problem-solving, understanding, as well as degree of conflict have a substantial impact on the management of a T1DM child. In general, highly-supported T1DM youth—in that parents are involved in management—have better regimen adherence and outcomes (Grey, Davidson, Boland, & Tamborlane, 2001; Schafer, McCaul, & Glasgow, 1986). Parental monitoring of management may produce indirect beneficial effects on glycemic control (Ellis et al., 2007). And for the most part, T1DM does not pose significantly abnormal challenges within the family environment, and communication is often characterized by empathy, goals for management are clearly communicated, and problem-solving is encouraged. When responsibilities given by parents are developmentally appropriate and tailored to the child’s psychological maturity, treatment adherence is better and there are fewer dangerous complications requiring hospitalization (Wysocki et al., 1996).

According to a review by Delamater (2009), however, when family conflict is present, decreased glycemic control and disrupted treatment adherence is common. Diabetes-related conflict may emerge from disagreements about how involved parents are and children questioning their parents on how management should be accomplished (Miller-Johnson et al., 1994). One prospective study of low-SES inner-city children examined the effects of family

adaptability and family cohesion on treatment adherence and glycemic control (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004). Their results indicate that higher family cohesion protects against diabetes-related risk, perhaps because children perceive their families to be more closely monitoring their enactment of adaptive health behaviors. This effect was more robust for adolescent girls than boys, perhaps because girls may utilize family communication more effectively to manage stress and problems. Age effects were seen in relation to family adaptability; younger children seem to benefit more from rules and structure compared to older ones, who might feel stifled and more stressed by controlling families. The authors suggest that family-level interventions targeting healthy family relationships and supportive communication—as well as encouraging flexibility in terms of the ability to shift autonomy and control from the parent to the child as the child grows up—would be beneficial to improve glucose regulation in the long-term.

Moreover, there is an issue of parental emotional adjustment following the T1DM diagnosis. Parents carry a burden of caring for their child, which significantly increases stress. In fact, such stress seems to create greater risk for psychological problems for mothers after their child is diagnosed; problems tend to be depression (in approximately one-third of mothers), and PTSD (in nearly one-fourth of mothers and one-fifth of fathers six weeks after diagnosis) (Delamater, 2009). Parents worry greatly about possibilities of hypoglycemic and hyperglycemic episodes in addition to changes in routines of their children that can precipitate these. Coping strategies of parents, such as their willingness to be knowledgeable about the disease, their degree of communication with professionals, seem to relate to their child's health outcomes as well (Halvorson, Yasuda, Carpenter, & Kaiserman, 2005).

Type 1 Diabetes Mellitus in Adolescents: A Vulnerable Developmental Period

The transition between the school-aged child (approximately seven to twelve years old) and the adolescent/teenager (aged thirteen to eighteen) presents a much greater challenge in the management of T1DM relative to the other developmental stages. There are critical biological, cognitive, emotional, social, and academic changes that occur during this transition that place the early adolescent at high-risk for diabetic complications. Glycemic control typically diminishes during adolescence, which is partially attributable to hormonal changes and various behavioral problems (Dabadghao, Vidmar, & Cameron, 2008; Pound, Sturrock, & Jeffcoate, 1996). Non-adherence to treatment during adolescence, however, represents the other major risk factor in lowered glycemic control (Du Pasquier-Fediaevsky, Chwalow, & Tubiana-Rufi, 2005).

According to Erik Erikson's theory of psychosocial development, a primary task of adolescence is to consider, test, integrate, refine, and solidify one's identity, or sense of self (Erikson, 1994). Broadly, the development of a clear and consistent sense of self involves a degree of separation and autonomy from parents (Paikoff & Brooks-Gunn, 1991), and peer relationships begin to have greater influence on one's developing identity. Diabetes and its complex management present an additional challenge and stressor for the adolescent. Diabetes affects multiple aspects of development within this phase, including child-parent relationships, quality of life, school or work difficulties, and involves having to respond and adapt to the disease within the context of identity establishment. Halvorson, Yasuda, Carpenter, and Kaiserman (2005) describe age-specific challenges of diabetes management from the following perspectives: cognitive ability, moral development, emotional maturity, social relationships, personal responsibility, academic functioning, extracurricular activities, and response to incentives, and several of these challenges are reviewed here.

Changes in cognitive processes. With regard to cognitive changes, adolescence is characterized by the development of formal operations. It is thought that the shift to abstract reasoning, where the adolescent gains the ability to generate hypotheses and deduce consequences, may produce increased feelings of vulnerability as they gain a wider understanding of the realities of the disease. The greater use of hypothetical and deductive reasoning may create negative emotional reactions as adolescents consider the potential future complications and challenges of their illness. A deeper understanding of the illness coupled with a low self-efficacy to modify or control the inevitable complications may be very worrisome for the patient. At the same time, many adolescents may lack knowledge about long-term complications, and therefore perceive that they are not vulnerable (and thus increases the risk of deteriorating glycemic control) (Timms & Lowes, 1999).

Differences in particular aspects of cognitive processing may explain why some adolescents are at greater risk for poor psychological functioning and health outcomes. For instance, the concept of health locus of control refers to individuals' beliefs about their ability to control events in their lives. How the T1DM adolescent perceives their own ability to be responsible for diabetes management matters; those with a greater internal locus of control maintained proper self-management in one study (Hocking & Lochman, 2005). Greater perceived susceptibility and illness severity were also related to better adherence in this study.

Additionally, there exists variability in the extent to which T1DM adolescents incorporate diabetes into their self-concept. How readily they define themselves as a diabetic is referred to as "illness centrality" (Helgeson & Novak, 2007), and whether they perceive their illness in positive or negative terms has implications self-esteem and shame. Helgeson and Novak found that female T1DM adolescents were more likely to perceive diabetes as central to their self-

concept, and the extent to which females had negative illness centrality (perceived their T1DM very negatively) predicted depression, anxiety, and anger compared females who perceived their T1DM less negatively. Non-negative illness centrality was found to be linked to appropriate self-care behavior.

Changes in familial and social relationships. Next, social and interpersonal factors assume an important role in self-management behaviors in adolescence. Importantly, diabetes management is often viewed by many members of the adolescent's family, particularly the parents, as a collaborative process. As the adolescent establishes greater autonomy from his or her parents, their involvement in daily management can be stressful and a major source of tension, resentment, or conflict (Wysocki, Buckloh, Lochrie, & Antal, 2005). Adolescents may reject assistance or supervision from their parents as they desire greater independence and fewer restrictions on diet and other management decisions. They may begin to question their decisions and perceive their parents as intrusive and overly-directive. In addition, feelings related to self-efficacy and disempowerment emerge in that parents may inadvertently suggest the adolescents are incapable of self-management. Finally, adolescents may also become aware of the impact of their disease on their parents' stress levels, creating a sense of guilt.

With regard to relationships with peers, adolescence is characterized by increased time socializing within peer groups. Peers can be very supportive in providing emotional support and company (e.g., being an exercise partner) and accommodations in lifestyle such as accommodating meals (Hains et al., 2007; La Greca et al., 1995). Peers tend to less frequently provide specific diabetes-related assistance, which is more often provided by the family members (Bearman & La Greca, 2002). Peer support has been shown to affect adherence to treatment in some cases (Kyngas, 2000; Skinner & Hampson, 1998). However, peer pressure

also exists, and adolescents are more susceptible to poorer adherence behaviors in order to gain peer approval (Berlin et al., 2006; Helgeson et al., 2007). Changes in peer relationships often present opportunities to explore risky behaviors, such as smoking cigarettes, drinking alcohol, or consuming other substances, as well as sexual experimentation, each of which impacts glycemic control directly and indirectly. Adolescents may begin to recognize their greater desire to fit into peer groups, and adolescent egocentrism can lead to acute self-consciousness. This can especially be true for diabetes management tasks such as administering insulin injections or pin-prick blood tests, which can bring shame or feelings of “being different” when the wish to fit in to peer groups is greatest.

Lifestyle changes. Multiple transitions take place in the adolescents’ schedules, which can be disruptive to routines for adherence. With more extracurricular activities and time spent outside the home, the responsibility of care must shift from the parent to the child for the first time. At this stage, school days and extracurricular activities are carried on for longer durations of time, and classes or work schedules may interfere with established patterns of blood testing. Weekday and weekend schedules may differ considerably. Schedules may also change the amount of physical exercise the adolescent is accustomed to doing. For example, the adolescent may become more sedentary or may begin to participate on a school sports team, and each route may increase the probability of hyper- or hypoglycemic episodes, respectively. Adolescents may find carrying diabetes management supplies throughout the hectic day to be inconvenient and irritating, and may modify their insulin injections to fit with their schedule. Furthermore, meals and snacks are not always well-coordinated with school and work, so timing of meals may be more erratic; this is complicated by the increased appetite and calorie requirements of an adolescent. More meals may be eaten away from home (e.g., fast food), and such foods may

have unfamiliar amounts of carbohydrates and fats, making insulin injections more complicated and the probability of a hyperglycemic or hypoglycemic episode more likely. Driving for the first time can present dangerous circumstances if hypoglycemic episodes are experienced frequently. Indeed, the American Diabetes Association has recommended that a management regimen be specifically tailored to the adolescent's ever-evolving lifestyle and developmental course in order to minimize significant complications like hypoglycemic episodes (American Diabetes Association, 1997).

Biological changes. Finally, the hormonal changes caused by puberty have direct effects on glucose metabolism and regulation. The onset of puberty poses the biggest challenge for the adolescent, as he or she is experiencing frequent and more intense glycemic fluctuations for the first time. Biologically, there is increased insulin resistance secondary to increased levels of growth hormone (Du Pasquier-Fediaevsky & Tubiana-Rufi, 1999). Puberty also incites increased appetite and weight. Compared to prepubertal children, pubertal adolescents have been shown to have between 25 and 30 percent less insulin response (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986). As a whole, adolescent girls tend to have poorer metabolic control during this period, perhaps due to more frequent fluctuations in hormone levels (Mellin, Neumark-Sztainer, & Patterson, 2004). Hormonal factors can interfere with the self-care behaviors of an adolescent in that even if an adolescent is strictly adhering to treatment, observing decreased glycemic control can be discouraging and reduce motivation to engage in self-care (Du Pasquier-Fediaevsky et al., 2005).

Glycemic control in adolescents. The Diabetes Control and Complications Trial (DCCT) demonstrated that HbA_{1c} levels (a glycemic control biomarker; representative of mean blood glucose over the past three months) are significantly higher in the adolescent cohort compared to

adult cohorts. Specifically, HbA_{1c} levels were often greater than 8.0% (for reference, the normal range for the HbA_{1c} test is 4.8–5.9% in non-diabetic individuals; the recommended HbA_{1c} target is below 7.0% for adult patients and below 7.5% for adolescents) (American Diabetes Association, 2009). Additionally, there was a two- to four-fold increase in hypoglycemic risk compared to other age groups (DCCT, 1994). These patients (between the ages of 13 and 17), however, did benefit from intensive diabetes management; mean HbA_{1c} levels decreased by 1.5–2.0% as a result (DCCT).

In a major cross-sectional study of children and adolescents with T1DM from 18 countries in Europe, Asia, and North America, similar results regarding glycemic control were reported (Mortensen et al., 1998). Mortensen et al. discovered that while mean HbA_{1c} in children younger than 11 years was 8.3%, adolescents between the ages of 12 and 18 had a mean HbA_{1c} of 8.9% (and 41% of children had an HbA_{1c} below 8%, while only 29% of adolescents did). This result was especially interesting as the adolescents received insulin three times (as opposed to only twice) daily. The authors found that these findings persisted even when given more daily injections, and therefore concluded that non-biological variables such as psychological states and behaviors may be as important as injection frequency and dose in achieving good glycemic control.

Empirically-Supported Psychological Interventions for T1DM Adolescents

Given the substantial evidence of how the many psychological and behavioral factors interact with T1DM, psychological intervention research in this population is an exceptionally well-studied area of research. This review focuses upon the most robust clinical trials that have demonstrated the greatest empirical support.

One of the earliest exhaustive reviews of psychological and psychosocial interventions in this population was conducted by Rubin and Peyrot (1992). At that time, the authors claimed that the volume and quality of research dedicated to this area was “meager,” and the authors presented methodological and statistical concerns. They suggested that more robust, systematic clinical trials with control groups and representative samples be conducted. Nearly ten years later, Lemanek, Kamps, and Chung (2001) published a review of psychological interventions for non-adherence for several chronic illnesses (T1DM, juvenile rheumatoid arthritis, and asthma), and classified intervention studies for all three chronic disease using Chambless criteria (“promising,” “probably efficacious,” and “well-established”) (Chambless & Hollon, 1998). The authors concluded that cognitive-behavioral strategies are “promising” and “multi-component packages and operant learning procedures” are “probably efficacious” (Lemanek et al., 2001), identifying the broad types of interventions that would most likely have the most efficacious results on T1DM outcomes.

Other research groups have since published review papers that synthesize and analyze more specific aspects of psychological interventions for the T1DM population (Delamater et al., 2001; Hampson et al., 2000; Winkley, Landau, Eisler, & Ismail, 2006; Wysocki, 2006). The components of these largely individual and group (family)-level behavioral interventions include principles of operant conditioning in order to shape adaptive health behavior. For example, in his review, Drotar (2006) writes that “goal setting, self-monitoring, positive reinforcement, behavioral contacts, supportive parental communications, and appropriate sharing of responsibility for diabetes management” as well as psychoeducation, coping skills training, problem-solving skills, and stress management (p. 145) are each shown to produce positive effects in adherence, glycemic control, psychosocial functioning, and quality of life. Specifically,

the most common interventions included skills training, family-related interventions, dietary interventions, and problem-solving interventions. La Greca and Mackey (2009) also point out that elements of individual interventions for T1DM adolescents often include behavioral change, stress management, identification of coping mechanisms, and exploration of issues pertaining to adherence.

These interventions can be short-term and focused or long-term and intensive. Interventions are sometimes based on theoretical principles, most often family therapy, social learning theory, and behavioral principles (Hampson et al., 2000). Delamater et al. (2001) points out, however, that methodological problems inherent in non-randomized controlled trials (e.g., the lack of a control group, a small sample size, etc.) limit conclusions that can be drawn from many studies.

Perhaps one of the most clinically-relevant reviews was conducted by Hampson et al., (2000), in which the authors evaluated the effectiveness of 64 behavioral interventions specifically for T1DM adolescents (aged 9–21), 35 of which implemented a control group design. The review also included effect sizes (ES) from randomized control trials, useful for comparing components of multi-armed interventions. For each intervention, the authors report a mean effect size for each category of outcome variable (psychosocial, glycemic control, knowledge, self-management, etc.); the largest mean effect sizes were obtained for psychosocial outcomes (0.37), followed by the ES for HbA_{1c} (0.33), self-management (-0.15), and knowledge (0.16); the overall mean ES across all outcomes was 0.33 (2000). Overall, the authors concluded that behavioral interventions are moderately effective, but pointed out methodological limitations inherent in many of the reviewed studies. These limitations are important to consider in program planning. For example, less than 50% of the reviewed interventions were theoretically-grounded;

however, those that were driven by theory generated larger effect sizes. A little over one-half of the studies targeted glycemic control as the primary outcome, but the authors suggest that behavioral interventions should target behavioral goals such as adherence. Hence, theoretical principles should guide development of treatment goals, treatment strategies and approaches, and implementation.

Cognitive-Behavioral Therapy in T1DM

Cognitive-behavioral approaches are well-suited to address the vulnerability of the T1DM population due to decreased adherence to self-management behaviors because cognitive-behavioral therapy (CBT) emphasizes teaching and practicing coping skills, problem-solving skills, and self-monitoring health behaviors. Each emphasis can directly impact adherence, psychological diabetes-related distress, and ultimately the overall management and prognosis of the disease. A cognitive-behavioral model of T1DM is discussed below, and will be followed by a discussion of intervention studies utilizing such approaches within this patient population.

A cognitive-behavioral model of type 1 diabetes. Social cognitive theories of health behavior change suggest that beliefs and attitudes about the self, illness, and treatment for the illness significantly influence coping and problem-solving behaviors, which, in turn, predict the course and prognosis of the disease. Adolescents who hold negative beliefs about diabetes, for example, may have decreased motivation to engage in healthy self-care behaviors, thereby influencing glycemic control and diabetes-related complications. Theories underlying CBT assume that thoughts and beliefs interact with affective states and have significant implications on how one copes with the daily demands of diabetes.

CBT, originally developed for the treatment of mood disorders, has been applied widely within behavioral medicine settings addressing chronic illnesses. Within the diabetes frame,

CBT posits that cognitions (perceptions, thoughts, and beliefs), emotions, and behaviors (actions) interact to affect the diabetic's functioning, or the way in which he or she manages diabetes.

Core beliefs regarding the self, others, and the world ultimately generate automatic thoughts. In T1DM adolescents, beliefs related to failure tend to be the most commonly reported (e.g., "I will fail no matter what," "others never have to deal with failure," and "diabetes interferes with everything in my life"). Such core beliefs may give rise to intermediate beliefs, or attitudes that are pessimistic toward diabetes and the adolescent him/herself (e.g., "it doesn't matter how hard I try, I'll still get the complications," "if I am hyperglycemic one time, then I have messed up entirely and am a terrible patient," and "I can't stand living with diabetes.").

Such irrational core and intermediate beliefs can produce automatic thoughts that are characterized by cognitive distortions such as over-generalizing, catastrophizing, and all-or-nothing thinking. Examples of automatic thoughts may include, "now that my numbers were high today, they will be high every day and I will never be able to control them," or "because I wasn't able to control my glucose today, I'm a person who is incapable of helping herself," or "I now have major complications that will kill me sooner than everyone else." Automatic thoughts that fall under the category of black-and-white thinking include the belief that if one is not a "perfect adherer" then one should not try at all and "let it all go." Also, if there are beliefs that the diabetic has about herself that she is "unable to lead a 'normal' lifestyle with diabetes" then she might think, "my self-care tasks aren't worth my time and attention; they only interfere with my life." This might be especially salient in peer group contexts, where self-consciousness is high.

In the CBT model, beliefs that T1DM adolescents have about themselves, their illness, and the outcome of treatment will have a major impact on the choice to adopt healthy behaviors

or not. For example, if an adolescent has the belief that administering insulin after a prior slip-up is worthwhile, he or she may be more likely to hold an optimistic attitude, have a decreased tendency to catastrophize, and be more likely to behave in a healthy way. In contrast, beliefs that pertain to failure are apt to contribute to feelings of hopelessness, sadness, pessimism, frustration, anger, and guilt. Negative emotions, particularly related to depressive and anxious symptoms, that emanate from distorted thinking patterns often result in maladaptive or inadequate coping behaviors, including avoidance, ventilation, and rumination. Negative affect is an antecedent condition to poor self-management and control, inciting more and prolonged negative feelings, and ultimately leading to a state of emotional exhaustion that Polonsky (1999) refers to as “diabetes burnout.”

Therefore, one’s emotional response to automatic thoughts and behaviors has a potentially major impact on behaviors—specifically treatment adherence, which in and of itself assumes a central role in long-term diabetes-related morbidity and mortality. The goal of CBT treatment in T1DM, therefore, is to teach patients to identify and evaluate their dysfunctional beliefs and to replace these beliefs with more realistic and rational ones, particularly about the meaning and perception of failure. Amsberg et al. (2009) asserts that because CBT assists individuals in increasing awareness about cognitive, affective, and behavioral processes related to self-management, they will be able to utilize such tools to determine effective coping strategies.

Behaviors are also very likely to impact cognitions and beliefs in this model, as multiple failures in achieving proper self-management contribute to negative beliefs related to one’s capacity for achieving success and about the illness itself (e.g., that it cannot be managed or

overcome). In effect, such negative beliefs may serve to reinforce existing negative intermediate beliefs (and attitudes) towards diabetes.

Research evidence supports that cognitive appraisals assume a very important role in understanding how moderators such as stress and treatment adherence impact diabetes-related outcomes (both biological and psychological). Cognitive appraisals, as conceptualized by Lazarus and Folkman (1984), are the processes that one uses to evaluate a specific event; generally speaking, they are involved in an individual's reaction to perceived threat of illness, which impacts emotions, and, in turn, coping. Two forms of cognitive appraisal, primary and secondary appraisal, allow one to determine the significance of an event on well-being, and to evaluate coping resources and options to manage the event, respectively.

In primary appraisals, one appraises a situation as benign-positive, or as a harm, threat, or challenge. Diabetic patients often perceive their illness as a challenge rather than a threat or harm; such an appraisal refers to the perception that the demands of the disease are capable of being met or overcome by the individual (whereas harm describes the perception that damage has already occurred, and threat relates to anticipated harm or loss from the illness) (Murphy, Thompson, & Morris, 1997). A challenge appraisal, such as "I will compete and beat my diabetes" is linked to greater treatment adherence as it conveys one's willingness to confront barriers to adherence in an action-focused way. This appraisal may be due to diabetes' high relative survival rate. In terms of a secondary appraisal, diabetic patients may think, "I can do something about my diabetes" or "there are no options for me to take care of my diabetes" which impacts self-efficacy for adhering to the glycemic control regimen and influences how the adolescent navigates seeking support from others. In one study of the role of cognitive appraisal processes on adherence behavior among T1DM adolescents, Murphy et al. (1997) found that

esteem related to physical appearance accounted for the greatest variability in blood glucose monitoring behaviors, followed by perceived control over health when ill, and an external attributional style for negative events.

The CBT model, therefore, focuses on cognitive restructuring via identification of negative beliefs about self-esteem, perceived control, and the impact of diabetes on well-being—all of which can lead into reinforcing negative cycles—and the modification of such beliefs so as to enable more adaptive self-management behaviors. Behavioral change is viewed as key in terms of intervening via activity scheduling, cueing, self-reward, and stress-management techniques.

CBT intervention studies within the adult T1DM population. Several studies have examined CBT-based interventions in the T1DM adult population. Van der Ven et al. (2005) found that their CBT-based program for adult T1DM patients resulted in higher self-efficacy and lower diabetes-related distress, but did not result in improvement in glycemic control. This study, however, was not individually-tailored to the patient's needs and there was a limited focus on behavioral interventions. Amsberg et al. (2009) addressed these limitations in another CBT intervention study that incorporated both individual and group CBT and a structured maintenance program for behavior change. The results of this study indicated that significant differences in HbA_{1c} were observed as early as week eight of treatment and were maintained throughout the 48-week study; this was the first of the behavior-oriented interventions of T1DM adults that generated such significant effects. The authors pointed out, however, that decreased HbA_{1c} could represent an increase in the incidence of hypoglycemia among those in the CBT intervention, which “must be acknowledged as an important possible negative effect of the CBT program that needs to be weighed up against its benefits, and/or closely watched for...in the

future” (Amsberg, 2009, p. 78). Therefore, monitoring and staying observant of the multitude of variables, both positive and negative, that produce changes in adherence to treatment, is critical.

Other group CBT interventions have produced more modest effects on glycemic control. In a study by Snoek et al. (2001) of 24 poorly-controlled T1DM adult patients, mean HbA_{1c} decreased by 0.8% at follow-up (a modest yet clinically significant result) and also resulted in decreased diabetes-related emotional distress and improvements in blood glucose self-monitoring. A follow-up randomized control trial (Snoek et al., 2008) demonstrated that CBT was effective in lowering HbA_{1c} scores in patients with high baseline depression scores within one year of follow-up, but neither of these studies demonstrated statistically significant differences in HbA_{1c}.

CBT in the pediatric T1DM population. Within the pediatric population, several studies have examined the impact of CBT for T1DM adolescents with co-morbid depression, adjustment difficulties, and low glycemic control. One study used weekly group CBT for T1DM adolescents and aimed to reduce the intensity and duration of depressive symptoms, teach ways to prevent depression, increase patients’ sense of control of their lives, and improve glycemic control (Rossello & Jimenez, 2006). The authors found that while depressive symptoms and diabetes self-efficacy improved, no significant change in self-care behaviors or glycemic control were observed at a 12-week follow-up. The authors concluded that more directly targeting self-care behaviors during sessions would improve future studies as would integrating parental involvement. Other studies have more closely targeted and examined adherence behaviors following mixed group/individual CBT interventions (Cook, Herold, & Edidin, 2002; Hains, Davies, Parton, & Silverman, 2001; Mendez & Belendez, 1997; Silverman, Hains, Davies, & Parton, 2003), and although these studies demonstrated improvements in problem-solving, self-

management behaviors, emotional well-being and adjustment, and anxiety and stress, significant changes in glycemic control were not evidenced. There are many reasons for this, including physiological changes in adolescence, levels of baseline stress impacting glucose metabolism, and lack of basic knowledge regarding diabetes care. Further attention to clarify the relationship between behavior and glycemic control within this population is warranted in future studies. It is very promising, however, that psychological outcomes such as stress, anxiety, and depression appear impacted by CBT interventions, and further longer-term studies will likely clarify how these changes translate into changes in diabetic complications as T1DM adults.

Other Interventions for T1DM Adolescents

Coping skills interventions. Several studies have evaluated the effectiveness of coping skills interventions (Boardway, Delamater, Tomakowsky, & Gutai, 1993; Grey et al., 1998; Whittemore, Grey, Lindemann, Ambrosino, & Jaser, 2010). Coping skills training, as operationalized by Grey et al. (1998) involves social problem-solving, social skills training, cognitive behavior modification, and conflict resolution. Such training also involves replacing ineffective coping habits with more adaptive and constructive ones. Grey found that at three months follow-up, participants who received coping skills training had lower HbA_{1c} levels, higher diabetes self-efficacy, less distress about coping with diabetes, and perceived a less negative impact of T1DM on their quality of life. Coping interventions were based upon empirically-developed scenarios that were used for role-playing difficult social situations that would impact diabetes management. Furthermore, the communication skills required to negotiate with parents about responsibilities and communicate goals with health care providers is particularly important. This study was notable for its methodological rigor; it was a randomized control trial with a large sample size and measured multiple psychosocial and medical outcomes.

However, follow-up was limited to three months, and the sample was not representative of ethnic minority participants, so further study of coping skill interventions was recommended. Other types of coping skills interventions have been tested, including an Internet-based coping skills training program (Whittemore et al., 2010), which showed reasonable feasibility and acceptability, but such research is in its infancy and requires much greater development and evaluation.

Other types of individual- and group-level interventions. Other types of interventions include problem-solving, although there is less research that has isolated the singular effect of problem-solving on diabetes outcome, as it is often incorporated into other interventions (Cook et al., 2002; Hill-Briggs et al., 2007; McNally, Rohan, Pendley, Delamater, & Drotar, 2010; Toobert & Glasgow, 1991) and health-related quality of life studies (De Wit et al., 2008; Graue, Wentzel-Larsen, Hanestad, & Sovik, 2005). Interventions focusing on stress management have also been examined (Attari, Sartippour, Amini, & Haghghi, 2006; Boardway et al., 1993; Hains, Davies, Parton, Totka, & Amoroso-Camarata, 2000; Worrall-Davies, Holland, Berg, & Goodyer, 1999), which followed work demonstrating the links between perceived stress and diabetic outcomes.

Motivational interviewing has also been examined in this context; motivational interviewing targets multiple behaviors related to both medical and psychological illnesses in order to enhance intrinsic motivation to effect change in behavior (Miller & Rollnick, 2002). Four principles of motivational interviewing include expressions of empathy, roll with resistance, develop discrepancy, and support self-efficacy. Although motivational interviewing research in the T1DM adolescent population is limited, several studies have concluded that such interventions are efficacious for both individuals and groups (Channon, Smith, & Gregory, 2003;

Channon et al., 2007; Viner, Christie, Taylor, & Hey, 2003). These studies showed that motivational interviewing interventions were effective in lowering HbA_{1c} levels both post-intervention and at follow-up, and in improving measures of quality of life and wellness. Other interventions that have been shown to be moderately to strongly efficacious include telephone support, which uses principles of problem-solving and social learning theory (Howells et al., 2002). A case manager program called Care Ambassador, which utilizes case managers in the clinic to impact adherence was shown to improve glycemic control and decrease hospitalization rates and improved attendance at clinic visits (Svoren, Butler, Levine, Anderson, & Laffel, 2003). Psychoeducational interventions designed for clinicians who are part of the diabetes team also showed beneficial outcomes (McNamara et al., 2010). There are also additional psychosocial group interventions that have demonstrated positive effects on both psychosocial and medical outcomes (for a review, see Plante & Lobato, 2008). These include psychoeducational/didactic groups, and diabetes skills practice.

Family-level interventions. Many factors related to the adolescent's family, including family member relationships and communication, impact diabetes management during adolescence. Thus, therapies that target the family, particularly the parents, are crucial. Family problem-solving interventions were shown to be effective in decreasing diabetes-related family conflict, increasing treatment adherence, as well as increasing glycemic control (Anderson, Brackett, Ho, & Laffel, 1999; Laffel et al., 2003). Family-level interventions often include behavioral contracting and behavior modification and family problem-solving. Multisystemic therapy (MST) intervenes at the systemic level, is home-based, and involves families, schools, and peers (Ellis et al., 2004; Ellis et al., 2007). Behavioral family systems therapy for diabetes (BFST-D) has been tested in several randomized clinical trials by Wysocki and is a skills-based

intervention that targets family problem-solving, communication, strong beliefs, and family structure, and has been shown to have an impact on important psychological variables as well as biological ones, such as glycemic control (Wysocki, 2006; Wysocki et al., 2005; Wysocki, Greco, Harris, Bubb, & White, 2001; Wysocki et al., 2007; Wysocki et al., 2008). Family psychoeducational interventions have also been studied and have been shown to be effective (Christie et al., 2009; Satin, Lagreca, Zigo, & Skyler, 1989).

Approaches to Assessment of T1DM Adolescents

Approaches to assessment of diabetes among adolescent patients are widely studied (Wysocki, 2006). Assessment typically includes gathering information related to treatment regimen adherence behaviors, diabetes-related psychological stress, mood (and other psychological) symptoms, self-efficacy, and biological outcomes (such as HbA_{1c}). Measures pertaining to diabetes-related coping skills, problem-solving skills, risky behaviors, and family/peer communication may also be administered. Within the CBT model, instruments assessing frequency of behaviors and ratings of emotions and mood symptoms offer valuable information to the clinician in terms of assisting the patient in identifying connections between diabetes-related thoughts, feelings, and behaviors. Due to the complexity of factors predicting diabetes-related outcomes (both psychological and physiological), it is crucial that a comprehensive assessment approach be taken. A number of self-report measures and other assessment methods have been validated and empirically supported within the pediatric diabetes population, several of which are summarized below.

Self-reported behavioral self-management, while much more practical than direct continuous observation of behavior, offers only an approximation of treatment adherence. Self-report instruments and recall measures that are completed by the adolescents and their parents

have not been found to be significantly correlated with biological measures of glycemic control, as over-reporting management behaviors is common (Wing, Epstein, Nowalk, Scott, & Koeske, 1985). Nevertheless, several self-report instruments are available for use. A Self-Care Inventory consisting of 14 items of diabetes self-management tasks over the past three months, each of which are measured on a Likert scale is one example (Kovacs et al., 1990). The Summary of Self-Care Activities measures adherence to T1DM treatment and has demonstrated a reliability index of 0.79 (Schafer, Glasgow, & Mccaull, 1982). Stressors linked to diabetes may be assessed via the Problem Areas in Diabetes scale by Polonsky et al. (1995), which can allow the clinician to identify stressors impacting treatment and assist the patient in devising appropriate stress-management techniques. Diabetes-related stressors can also be measured with the Diabetes Stress Questionnaire (Boardway et al., 1993); this is a 65-item self-report inventory with high demonstrated internal consistency (Cronbach's $\alpha = 0.97$). Additionally, the Self-Efficacy for Diabetes Scale (SED) is a 35-item scale measuring self-perception or expectations of competence, power, and resources for successful management of T1DM (Grossman et al., 1987), and has a demonstrated reliability coefficient between 0.90 and 0.92.

Cognitive appraisals related to perceived threat of diabetes may be measured with the Cognitive Appraisal of Health Scale (T. A. Kessler, 1998), which assesses for both primary and secondary appraisals. Additionally, emotions and affect related to diabetes can be measured via self-report instruments such as the Hypoglycemia Fear Survey (Cox, Irvine, Gonderfrederick, Nowacek, & Butterfield, 1987) and other mood-specific measures that have been validated in the pediatric population (e.g., Children's Depression Inventory) (Kovacs, 1992).

Other measures are administered by clinicians. An example is the Diabetic Management Information Sheet (Kovacs et al., 1990), a semi-structured interview that allows the clinician to

collect diabetes-related information from parents, such as age of onset, emotional reactions to the diagnosis, adherence patterns, hospitalizations and ER visits, etc. Another example that has extensive research support is the 24-Hour Recall Interview (Johnson, Silverstein, Rosenbloom, Carter, & Cunningham, 1986), which consists of three interviews (which occur unannounced) whereby the interviewer helps the patient to reconstruct the diabetes-related events of the preceding 24 hours and measures 13 dimensions of self-care behavior. A structured interview called the Diabetes Self-Management Profile (Harris et al., 2000) measures the frequency of 25 self-management behaviors over the preceding 3-month period.

Finally, biological measures provide crucial information on health outcomes and are an important part of comprehensive assessment. HbA_{1c} is a routine measurement of glycemc control over the prior three months and is measured via a simple laboratory blood draw. Measurement of daily blood glucose is also often taken by downloading data from the blood glucose meter, which can store data over several weeks.

The Role of Cultural Diversity Factors on T1DM Outcomes

There is a substantial body of scientific literature documenting the influence of cultural variables on health outcomes in adult and pediatric diabetic patients. A recent systematic review of studies examining the relationships between demographic, interpersonal, and intrapersonal characteristics of T1DM youth on self-care and metabolic control identified multiple sociocultural variables that predict poorer T1DM outcomes (Neylon, O'Connell, Skinner, & Cameron, 2013). The review concluded that belonging to an ethnic minority group, being of lower SES, and being a child in single-parent family structure were the most robust demographic predictors of self-care and metabolic control. Across the literature base, within populations of

youth with type 1 diabetes, the influence of ethnicity and socioeconomic status (SES) on glycemic control is one of the most well-studied relationships.

Broadly, ethnic minority group status is correlated with poorer metabolic control. In fact, clinically significant health disparities persist in metabolic control such that relative to Caucasian T1DM youth, African-American and Hispanic T1DM youth have been demonstrated in multiple studies to have higher mean HbA_{1c} values (Delamater et al., 1999; Mayer-Davis et al., 2009). Hispanic T1DM youth, in one study, were measured to have HbA_{1c} levels 0.45% higher than non-Hispanic patients (Gallegos-Macias, Macias, Kaufman, Skipper, & Kalishman, 2003). Other studies measured disparities between African American and Caucasian pediatric patients as high as 1.5–1.9% (e.g., Ashraf, Li, Franklin, McCormick, & Moreland, 2009; Auslander, Thompson, Dreitzer, White, & Santiago, 1997). One retrospective review of T1DM patients under the age of 16 in New Zealand found that ethnicity had a greater impact on HbA_{1c} and episodes of moderate to severe hypoglycemia than socioeconomic status (Carter et al., 2008). This study concluded that Maori and Pacific T1DM youth had poorer metabolic control and were at more at risk for long-term complications than youth of European heritage. The SEARCH for Diabetes in Youth Study conducted a cross-sectional analysis of data from multiple sites across the United States and identified rates of poor glycemic control across ethnic minority T1DM youth as follows: African-American (36%), American Indian (52%), Hispanic (27%) and Asian/Pacific Islander (26%), compared to a prevalence of 12% for non-Hispanic white youth (Petitti et al., 2009). These differences in HbA_{1c} are strongly linked with greater morbidity, including a higher number of diabetic ketoacidosis-related hospitalizations, hypoglycemic episodes, microvascular damage, as well as mortality rates.

There is some evidence to suggest that specific management behaviors, such as blood glucose monitoring, adherence to dietary guidelines, insulin administration regimen, and exercise differ to some degree across ethnic groups (e.g., Swift, Chen, Hershberger, & Holmes, 2006), with Caucasian youth more frequently monitoring blood glucose than ethnic minority groups, for instance (e.g., Powell, Chen, Kumar, Stresand, & Holmes, 2013). Discrepancies in diabetes-related knowledge between Caucasian youth and parents and African-American youth and parents have also been documented (Powell et al., 2013). Caucasian youth have been documented to be more likely to use insulin pump therapy (Wang, Wiebe, & White, 2011), which may be associated with better glycemic control. However, there are other variables related to ethnic minority identity that may be more strongly linked to poorer outcomes, such as higher stress, but this area of research requires further study (Neylon et al., 2013).

Other sociocultural variables are thought to help explain the disparities in metabolic control and health outcomes in T1DM youth. It is important to note that many demographic variables co-occur in underserved and socioeconomically-disadvantaged populations. Ethnic minority status can, in some cases, be confounded by lower SES, reduced access to healthcare, and single-parent family structure. Socioeconomic status (SES) in particular is associated with reduced glycemic control in the T1DM pediatric population. Children of lower SES have been found to have poorer control compared to their counterparts of higher SES (Gallegos-Macias et al., 2003; Hassan et al., 2006), and in many cases, increases in HbA_{1c} were found in low-SES patients after controlling for ethnic minority status (e.g., Carter et al., 2008). One study indicated that children of families earning a median income of less than \$60,000 per year were at greatest risk for having the highest HbA_{1c} values (Springer et al., 2006). However, there is evidence that ethnic minorities living in higher-income neighborhoods actually experience more rapid

glycemic control deterioration (Wang et al., 2011); the authors of this study postulate that minority individuals living in “majority-race dense” (p. 574) neighborhoods may experience greater discrimination, social isolation, or acculturative stressors, which may help explain the poorer health outcome.

With regard to the family structure variables, T1DM adolescents from single-parent families are particularly vulnerable to having reduced metabolic control. A large, global study of T1DM adolescents showed that children whose parents lived separately had poorer glycemic control (Cameron et al., 2008). In one study utilizing a convenience sample of T1DM youth, children from single-parent families had a mean HbA_{1c} value that was 1.25% higher than children from two-parent families (Thompson, Auslander, & White, 2001). Children from single-parent homes were speculated in the Neylon et al. (2013) review to likely to have increased stress, fewer resources, and experience reduced family cohesion, which may contribute to lower adherence with daily management behaviors.

Attitudes and beliefs about T1DM have also been shown to differ across cultural groups, and it is important to explore these to understand how adolescents and their families cope with the illness and interact with health systems. One qualitative study using a semi-structured interview guide to ask open-ended questions to low-SES T1DM youth and parents of three ethnic groups was conducted in order to uncover themes of how T1DM was experienced emotionally (Edmonds-Myles, Tamborlane, & Grey, 2010). The study concluded that while emotional responses to T1DM was similar across Caucasian, African-American, and Hispanic families were similar in many ways (e.g., involving anxiety and fear), Hispanic families were more likely to be involved in diabetes care of the youth, felt more preoccupied and worried more frequently about the children, and generally experienced the disease as more burdensome. Hispanic

families cited also different food preferences and language barriers as being difficult to cope with. African-American and Hispanic families also reported more financial difficulties, which could create challenges with purchasing specific foods necessary for the T1DM child. The study's authors concluded that health care providers should consider offering support and educational groups that focus on reducing barriers within certain minority groups. It was also suggested that providers should consider communicating their acceptance of the role of spirituality in coping with the illness and showing sensitivity to immigration issues, modesty, and family structure.

Each of these variables represents highly worthwhile issues to consider when targeting at-risk populations of T1DM patients. In fact, many of the links between ethnic minority status, low SES, or single-parent families and poorer T1DM outcomes are thought to be mediated in part by stress and mental health issues as well as behavioral issues such as daily self-care management. To the extent that clinicians are aware of these health disparities in advance, triage approaches, assessment techniques, and clinical interventions can be more carefully and thoughtfully delivered. Knowledge of the most robust sociocultural determinants of metabolic control can help psychologists to predict challenges, barriers to care, and potential metabolic trajectories of their patients. Armed with knowledge about the ways in which cultural factors and psychological variables interact in this population of patients, issues can be more proactively and effectively dealt with early on—both on the level of the system and the individual.

Clinical implications of diversity factors. Disparities in diabetes-related outcomes between racial/ethnic groups as well as higher and lower SES groups may be partially explained by differences in knowledge about diabetes care and access to ongoing medical care (Powell et al., 2013). The current literature suggests that comprehensive programs that integrate diabetes

education in a culturally sensitive way, and addressing potential language and literacy barriers for parents would enhance health care utilization.

Among Hispanics, which represent the fastest-growing ethnic minority population in the United States, adherence to the T1DM regimen is closely linked to family and acculturation factors (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010). First, this study discussed how the emphasis on *familismo*, a term that describes the centrality of family relationships and the collective nature of responsibilities, is important in Hispanic youth's T1DM care. In fact, the study found a mediating effect of family support such that T1DM youth who were more independent in their management activities had poorer treatment adherence secondary to reduced family support for their care. Although causality could not be determined, the authors speculated that promoting family support behaviors as the adolescents become more autonomous in their care might improve adherence outcomes. Furthermore, the authors suggested that health care providers assess family support in their work with the T1DM youth and work with their families to enhance involvement of the family. Secondly, the study documented that within the population, generational status correlated with treatment adherence such that less acculturation and more recent generational status was predictive of more adaptive health behaviors. Therefore, it would be important that health care providers, including psychologists, to assess for acculturation during clinic visits in order to recognize whether more risk-taking behavior is taking place in families with increased acculturation to the United States. The role of protective factors, potentially involving more communal approaches to treatment, is important to understand in terms of how they may influence outcomes in this cultural group.

Among African-American youth, childhood factors may disproportionately place them at higher risk for metabolic deterioration in adolescence compared to Caucasian youth. A study

focusing on the longitudinal patterns of deterioration of metabolic control in T1DM adolescents found that, after controlling for income, Caucasian, Hispanic, and African-American youth demonstrated similar rates of deterioration across adolescence, but African-American children had a higher initial HbA_{1c} value (Wang et al., 2011), which may suggest that racial disparities may initially emerge within several years post-diagnosis. Therefore, in the African-American youth, it may particularly helpful to deliver interventions as early as possible after the T1DM diagnosis, focusing on parent-child and peer relationships.

Taken together, the studies on minority subgroups of T1DM youth underline the importance of the psychologist's holistic assessment of patients. Given the multiple systemic variables that predict health behaviors and medical outcomes, it is important to assess for the roles of the family structure and family support, acceptability of the outlined treatment course, emotional responses to the diagnosis and management, receptiveness of the regimen and recommendations, linguistic barriers, parental education and literacy, and any financial hardships in the T1DM youth's family. Providing culturally-appropriate care is contingent upon understanding these systemic issues and seeking to integrate the gathered information into every aspect of treatment.

Clinic-Integrated Program Implementation

Traditionally, mental health services have been delivered independently of medical care. In the past several years, however, the passage of health care reform (i.e., the Patient Protection and Affordable Care Act) has oriented the health care sector toward models emphasizing the integration of physical and mental health services. The goal of such interdisciplinary work is to improve treatment outcomes through coordinated care efforts that better enable patients to understand emotional responses to disease, develop coping strategies, increase compliance to

treatment regimens, improve quality of life, and reduce morbidity (Stancin, Perrin, & Ramirez, 2009). Integration of services is also critical for tailoring appropriate and timely interventions, building the trust and credibility of the providers, and reducing the stigma of mental health issues. Each of these independently affects patient outcomes. In fact, psychological interventions delivered in medical offices during routine clinic visits has demonstrated enhanced adherence and metabolic control in T1DM adolescents (Anderson et al., 1999; Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989).

At present, there are varying degrees to which psychologists and other health professionals collaborative to deliver services. For instance, it can range from a (a) a referral relationship between a physician and psychologist, to (b) a relationship wherein the psychologist is a separate practitioner but is located on the same site, to (c) a collaborative care model wherein the psychologist and the physician share cases, to (d) an integrated care model wherein the psychologist is a member of the care team (Stancin et al., 2009). Currently, integrated care exists predominantly in primary care clinics, patient-centered health homes, and accountable care organizations, and functions to expand access to mental health care for all patients. However, given that integrated care is a relatively new model of care, there are challenges and barriers to implementation. In the pediatric setting, R. Kessler (2009) recommends that attention to clinical, operational, and financial aspects of a program should be given, as they are each linked to the potential success of a program. Therefore, each of these three domains is reviewed below.

Clinical issues. Integrating psychological services into the broader healthcare system for pediatric patients with chronic disease is an emerging literature. Programs that have been developed vary substantially across settings. However, Kazak et al. (2007) have created a model of integrated care in the context of pediatric cancer, and this work offers a “blueprint” of how to

translate intervention research into clinical services for chronically ill children. The model first raises the notion of an “embedded psychologist” as opposed to a psychologist in a narrow consultant role; the psychologist within this program would have much greater collaboration with the entire team. Kazak’s framework suggests that the evidence-based practices selected in the integrated program be specifically targeted and tailored to the needs of the patient population. For instance, a range of services can be offered—from general educational interventions to unique, intensive services for children and families experiencing much greater distress. Kazak suggests that a program designed for medical clinic dissemination contain the following elements: (a) a screener to assess for psychosocial risk, which would allow the treatment team to divide the patients into groups of low, moderate, and high risk; and (b) provision of appropriate services on the basis of the screener.

Kazak et al. (2007) describe three groups of patients categorized by psychological risk level. First, the low-risk group comprises the patients who are generally high-functioning. This group would likely require attention to the most common difficulties experienced in the aftermath of diagnosis. Programmatic elements may include processing and reducing any experience of trauma, enhancing a sense of control and safety, providing psychoeducation, and facilitating parent or sibling groups. The moderate-risk group may be composed of patients undergoing more significant family stress, adjustment issues, or socioeconomic hardship. CBT interventions may be most effective for these patients, helping to address specific symptoms. Tailored interventions designed to decrease symptoms of anxiety, depression, and procedure-related distress are helpful. Finally, the high-risk group may have significant levels of distress and psychopathology. The program’s aim would be to provide more intensive individual and family services, working to create goals to enhance structure and safety in the environment.

Kazak et al. argue that interventions that promote adherence and family cohesion may be particularly important in ultimately cutting costs (e.g., through fewer clinic and hospital visits).

Earlier, Kazak et al. (2005) posed a series of questions through which feasibility of such a novel intervention program can be evaluated. Specifically, four aspects of feasibility are important: acceptability (was the intervention clinically relevant and accepted by the patients?); recruitment and retention (of the target population); timeline (was the intervention delivered in the appropriate timeframe?); and preliminary outcomes (of intervention effects).

Together, Kazak et al. (2005) provide a roadmap for the implementation and evaluation of a pediatric psychology service. A program that focuses on clinical effectiveness, alongside operational and financial issues has the potential for greater success.

Financial issues. Linking psychological and behavioral health services into medical care has been shown to be financially advantageous. For instance, Harris and Mertlich (2003) have shown that improved access to adherence-based interventions results in fewer hospitalizations of children with poorly-controlled diabetes mellitus. Given that costs of diabetic ketoacidosis-related hospitalizations can be greater than one billion dollars per year in the United States (Kitabchi et al., 2001), these services are considered quite cost-effective and provide a rationale for the provision of such.

To provide useful and sustainable pediatric psychology services, financial viability is paramount (Duke, Guion, Freeman, Wilson, & Harris, 2012). The services of psychologists within a comprehensive diabetes care team can be billed in three ways (Leichter, Dreelin, & Moore, 2004). First, Evaluation and Management (E&M) codes may be used, which implies that services are billed incident to the care of the physician. Secondly, psychotherapy codes can be billed if the patient has a psychiatric diagnosis. Third, Health and Behavior (H&B) codes are

used for assessment and intervention for evaluation of the “psychological, behavioral, emotional, cognitive, and social factors important to the prevention, treatment, or management of physical health problems” (as cited in Leichter et al., 2004, p. 129).

H&B codes were introduced by the American Psychological Association Practice Directorate to address the need and value of providing medical patients with psychological and behavioral services. This billing structure changed how psychologists in medical settings were compensated for their services for patients with primarily physical health conditions, in that they were designed to bill for the behavioral and psychological care of medical patients in busy clinic settings where preauthorization is not usually possible. H&B codes allow for the reimbursement of services targeting adherence, stress, coping, pain, and health-related behaviors. Prior to these codes, psychologists were reimbursed for services for this population under the Current Procedural Terminology (CPT) codes, but as described, use of these are dependent on the patient having a DSM-IV-TR mental health diagnosis, which can place significant pressure on providers. For an extended discussion on billing issues in pediatric psychology, please refer to Buckloh and Greco (2009).

One central advantage of an integrated care system is the possibility of the patient receiving psychological care and medical care on the same day. However, reimbursement for same-day services from two different providers can prove to be an impediment to timely integrated care. According to the Substance Abuse and Mental Health Service Administration, the federal government does not regulate whether two practitioners bill on the same day, but state Medicaid agencies may have rules that prohibit billing for both a physician and mental health visit on the same day (Kautz, Mauch, & Smith, 2008). If the same provider organization bills both visits, the second visit is often denied. However, in a state that allows for two services to be

billed on the same day (which 26 states currently allow), the behavioral health provider (i.e., psychologist) bills for the behavioral health service under his or her provider number, and the physician bills for medical services under his or her provider number. Therefore, it is recommended that any integrated program determine the billing rules by the payer (i.e., billing an Evaluation and Management visit the same day as a behavioral health visit; limits of the number of visits; requirements for authorization and pre-authorization). It is also recommended that the clinic seek out a complete understanding of the parameters of reimbursement for individual therapy, case management, etc.

Barriers to financing. Several challenges to appropriately financing pediatric psychological care exist (Duke et al., 2012). For instance, medical services generally earn greater revenue per unit of service compared to psychological services, but there are comparable overhead expenses. Health and Behavior (H&B) codes are not uniformly utilized across pediatric psychology settings and can be challenging to use. Specifically, difficulty obtaining authorization and reimbursement for outpatient and inpatient pediatric clinical services are frequent (i.e., insurance companies make assumptions that psychological services are to be billed under mental health coverage and subsequently deny H&B codes due to limits on mental health coverage) (Duke et al., 2012). The authors found that more than 75% of psychologist attempts to receive reimbursement are further denied even after directly contacting insurance companies. Therefore, several integrated programs have sustained significant financial losses when providing care to medical patients with complex psychological and behavioral demands. However, psychologists are engaging in advocacy for reimbursement of their services on both an individual case basis (i.e., through writing letters, making telephone calls to insurance companies and medical directors) and on a national basis (i.e., through APA).

Operational issues. Glasgow and Eakins (2000) describe the medical clinic as being well-positioned from a “conceptual and social-environmental influence perspective” (p. 142) to promote patient outcomes and decision-making processes of the treating providers. The operations and procedures that govern how providers deliver care and patients receive services in the integrated care context is reviewed here.

Importantly, the opportunity for physical space to be shared between physicians and psychologists facilitates greater cross-communication and collaboration. When a referral is made to a separate psychological services unit, it is sometimes perceived by patients as stigmatizing, and can present a greater burden to the patient who must schedule and coordinate two separate appointments. Having shared office space and coordinated appointment scheduling offers patients a “one-stop shop.” In a typical integrated care setting, a patient makes one appointment with the team. Prior to the patient arriving at the clinic, the patient may be mailed self-report assessments to complete. The patient arrives at the clinic and may be asked to complete measures on a computer or by hand. The patient then meets with his or her physician for the physical examination, assessment of their self-management, and receives orders for laboratory tests. The psychologist would then enter the room after the physician and conduct or review assessments, or follow-up on the behavioral health aspects of treatment. Each provider determines the plan for his or her respective treatments. Seeing both providers may reinforce particular messages, goals, and interventions and enhance understanding, credibility and compliance. Indeed, patients are more likely to follow-through on psychological referrals and understand the rationale for treatment when it is presented within an integrated setting (Glasgow & Eakins, 2000). Following the patient visit, the members of the team meet together to discuss the therapeutic goals and the plan for the next visit. This approach enables each provider to

reinforce one another's messages of health promotion and maintenance to the patient in subsequent visits. A discussion of any barriers to reach goals and possible strategies to modify treatment are discussed. Holding a discussion at that time point enhances clarity on the plan, and vastly reduces the need for inter-team follow-up (i.e., reducing writing and reading of reports, telephone calls, etc.).

From the provider perspective, an integrated program allows for regular case conferences between the physicians, psychologists, nurses, and diabetes educators, allowing efficient and timely discussions of patient management goals and plans. Glasgow and Eakins (2000) point out that collaborative goal-setting for patients and opportunities for coordinated intervention are much more likely to occur within shared office space. This removes some of the inherent impediments to a multi-disciplinary care model because key stakeholders and patients are physically present and can achieve the benefits of coordination without the barriers of waiting for communication by phone or email. Case conferences also provide an opportunity for communication about the most recent advances in biopsychosocial issues in diabetes. It is important to note, however, that a psychologist in a multi-disciplinary team may be vulnerable to encountering some resistance and attitudinal barriers from physicians and nurses who are predominant in a medical "home," and who likely have different perspectives on treatment based upon their training. Thus, logistically, this sort of program requires an agreement between all providers on the administrative procedures, screening protocols, intervention goals and activities, and follow-up care.

The psychologist has a unique role on the team, and carries out traditional interventions for the most part, but in a non-traditional setting (Schroeder, 1999). Specifically, given the number of adjustment-related problems post-diagnosis and the vulnerable and risky period of

adolescence, the psychologist may be able to offer early detection of psychological disorders, thereby enhancing treatment options and medical outcomes. This includes assessment of emotional well-being, psychopathology, and high-risk behaviors, coping, and the adolescent's self-management educational needs. Psychologists also provide psychotherapy services. Much psychotherapy in this context centers around using behavioral self-management strategies (reinforcement of healthy behaviors and habits, for example, particularly during the initial period post-diagnosis) (Clement, 1995). One meta-analysis (Hampson et al., 2000) found that behavioral interventions in this context were most commonly group-based (nearly half), compared to individually or family-based (22.9% and 14.3%, respectively). Crisis intervention and serving as a consultant/liaison for clinicians and families are additional roles. They may also provide and develop comprehensive and tailored psychoeducational services and materials for patients, their families, and healthcare professionals. Finally, psychologists are in the position to provide information to diabetes professionals regarding how to refer patients and families for appropriate psychological services. Thus, in integrated care, psychologists broaden their conception of their role as mental health practitioner to effect change individually and systematically.

Chapter 3: Methodology

The chief goals of the dissertation were to design a program that appropriately addresses the psychological care of Type 1 diabetic adolescents, to format the program for integration into the tertiary medical clinic setting, and to design an evaluation tool that can be used to evaluate the program for clinical utility in future studies. These objectives were accomplished by systematically reviewing and analyzing two major bodies of literature: psychological functioning in Type 1 diabetic adolescents, and strategies on delivering psychological services in the medical setting.

Rationale

Although numerous studies have identified specific components of interventions that have been shown to be generally effective in improving psychological and behavioral outcomes for adolescents (e.g., problem-solving, coping skills training, stress management, conflict resolution, motivational interviewing, etc.), never before have each of the tested individual interventions been integrated to create a comprehensive, multi-level program for this population. [For definitional purposes, the program is described as “comprehensive” because it targets (either directly or indirectly) psychological, behavioral, social, academic, and physical health outcomes. The “multi-level” nature of the program refers to its ability to intervene on two levels to optimize diabetes-related outcomes: the individual patient and the family.] Furthermore, no comprehensive program to the investigator’s knowledge has been specifically designed for implementation in an integrated care context, where adolescent T1DM patients are assessed and treated in a holistic manner by a team of collaborating mental health and medical professionals. Therefore, the program represents a new model of delivery of psychological services for a high-risk subgroup of T1DM patients (adolescents) that is based upon empirically-validated

intervention studies. It is beyond the scope of this dissertation to actually implement the proposed intervention (i.e., conduct a clinical trial).

A proposed evaluation measure, designed to identify strengths and limitations of both the programmatic content (e.g., interventions) and its model of care delivery is included for the purposes of enabling future studies to collect feedback on implementation issues. Given the goal of formatting the program for use in an integrated care environment, the survey also includes items assessing professional opinions on integrated care in a broader sense. Therefore, the evaluation tool can be used in future studies to measure professionals' attitudes and beliefs on the general concept of integrated care models. The survey could also potentially guide program implementation and investigation by other researchers in future investigation. It can serve to describe the set of observations and feedback from experts prior to program implementation, for instance. It may also lend itself to describing the professional characteristics that participants possess in terms of attitudes about integrated care, given the recent changes in healthcare policies.

This chapter is focused on describing the literature review strategies and the program development methodologies used in this dissertation. First, a comprehensive review of the existing literature on the relationships between psychological/behavioral variables and T1DM adolescent health served to primarily inform the content of the comprehensive program (i.e., treatment modalities, symptom assessment procedures). A second body of literature was reviewed to focus on psychological services delivery issues within the pediatric chronic disease context. This complementary literature review aimed to guide the creation of a program model designed for delivery within the integrated care setting.

The second phase of the study consisted of the development and creation of the program itself. The program, written in handbook format, can be found in Appendix A. Within the

program, the rationale for its creation and its overarching framework and goals were outlined. Details of program implementation were discussed. With regard to specific therapeutic content for individual- and group-level programming, detailed descriptions of cognitive-behavioral techniques were given particular attention, given that CBT techniques have the greatest empirical support within this population. Other interventions chosen for inclusion in the program, such as family psychotherapy, family psychoeducation, and coping skills training, were described in briefer terms, and the rationale for their inclusion was presented. Lastly, the evaluation tool that may be used in future studies to gather expert feedback from clinician evaluators was discussed. Suggestions for future use of this measure were described. The evaluation survey can be found in Appendix B.

Literature Review and Analysis Procedures

Identification of source material and study selection. Two major bodies of literature were reviewed for the conceptualization and development of the program. The first literature review focused on how the diagnosis of T1DM impacts adolescents' psychological functioning and vice versa. Specifically, this literature search focused on the following domains: epidemiological data related to T1DM and psychological/psychiatric risk factors within the T1DM adolescent population; medical treatment of pediatric T1DM patients; specific challenges in the psychological care of pediatric T1DM patients; effects of psychological stress on T1DM; effects of coping styles on medical outcomes (i.e., glycemic control); the effects of health beliefs and cognitive appraisals on T1DM; psychiatric diagnoses within T1DM adolescents; patient adjustment to the T1DM diagnosis; family adjustment to the diagnosis; the vulnerable developmental period of adolescence for T1DM patients; empirically-supported psychological interventions for diabetic adolescents (i.e., individual, group, family-based, school-based, etc.);

the influence of cultural diversity on T1DM outcomes; and assessment of functioning of diabetic adolescents.

The second body of literature centered upon the delivery of psychological services to chronic disease pediatric patients within medical settings. Existing models of integrated care and recommendations for how to apply psychological interventions in medical clinics were discussed. Economic considerations such as reimbursement for mental health services were highlighted. Finally, a discussion of the operational procedures that guide collaboration within interdisciplinary care teams was included.

Search strategies. The literature was utilized to develop the treatment model. Research databases such as PsycINFO, PubMed, and Web of Science were used to compile theoretical background information and data on the extant experimental, correlational, and intervention studies. Peer-reviewed journals reviewed include *Journal of Health Psychology*, *Journal of Pediatric Psychology*, *Diabetes Care*, *Pediatric Diabetes*, etc. In addition to resources gathered through online research databases, scholarly textbooks were reviewed (including but not limited to handbooks and textbooks such as the *Handbook of Pediatric Psychology*). National health organizations (e.g., Centers for Disease Control and Prevention, 2011) were consulted for the most recent epidemiological and medical data pertaining to T1DM.

To guide the literature search in a systematic fashion, various combinations of the following keywords were entered into the databases: type 1 diabetes mellitus, adolescents, cognitive-behavioral interventions, family therapy, T1DM treatment, T1DM interventions, social support, stress and coping, health services delivery, integrated care, multidisciplinary care clinics, chronic disease models of integrated care, psychological treatment of chronic disease, psychosocial interventions, etc. Inclusion criteria include the time frame of publication (within

the past 30 years, given significant biomedical advances in the study of T1DM), and the age group of the patients (age 18 and younger, given the target audience of the program). The program was based in part, however, from published findings from integrated care programs that utilized adult participants, given the limited number of pediatric chronic illness psychological intervention programs published.

Development of the Program Content

Findings from the comprehensive literature review were systematically evaluated to determine the content of the program's assessment and treatment approaches. The researcher selected several of the most efficacious aspects of interventions targeting key psychological and medical outcomes that were described as the most impactful in the literature. Then, applying the recommendations discussed in the health services delivery literature, the program content was designed for delivery in the most feasible and effective way. Therefore, the content and delivery approaches are based on the fundamentals of successful integrated care models. The interventions complement and build upon one another.

Based upon the identification of these critical programmatic elements and implementation procedures, the program was created. The program was written in handbook format, with chapters that include both background information on the disease and the population, suggested interventions, routes of program delivery, and suggestions for the evaluation of the program prior to its implementation. The program handbook was organized as follows.

1. The program opens with a discussion of the purpose and goals of the program.
2. The next chapter describes critical background information on Type 1 diabetes in adolescents and discusses the disease's psychological sequelae and impacts.

3. The following chapter proposes an implementation plan that provides details about developing a team of health care providers for the program. Ideas for financing and staffing the services are included.

4. An outline of all elements of services delivered by psychologists is introduced. The focus of the program's curriculum is cognitive-behavioral interventions for both individual and group sessions, given that CBT has the greatest empirical support for this population. A suggested blueprint for the application of the various programmatic elements is included.

5. A discussion of how to adapt to limitations of the proposed program with respect to diversity of the patients and the settings in which it could be implemented is provided. Specifically, recommendations for understanding cultural diversity factors in the context of psychological assessment and intervention in the program is discussed. Specific suggestions are given about how the program may be implemented in a non-medical clinic setting (i.e., the community) in order to enhance reach and access to communities that may have fewer financial resources.

6. The program handbook concludes with a discussion of ways in which the program could be evaluated prior to implementation. An evaluation tool is provided.

Program intervention selection process. The program was based upon the specific key attributes of successful comprehensive programs as described in the literature. It has been suggested that dismantling large intervention studies to identify the components that are most likely to reliably and feasibly produce change in the target population is an important step the field must take (Plante & Lobato, 2008). In fact, Drotar (2006) has recommended that intervention studies targeting pediatric patients aim to examine the effects of combining multiple specific interventions that had been shown in prior research to individually be effective. In other

words, the literature suggests that the creation of a “customized package” of efficacious interventions, tailored to the population’s needs and goals may be most efficacious. Therefore, this program’s main objective was to build in pre-validated programmatic elements that can align and synergize in a fashion that resulted in the greatest potential for improved health outcomes in adolescents with T1DM.

Several basic principles guided the creation of the program. First, interventions selected must have been theoretically-grounded and driven by specific theoretical tenets. Furthermore, specific categories of interventions had to have been tested in methodologically rigorous trials that utilized valid assessment instruments. Thus, inclusion criteria for the program included interventions that are empirically-validated or evidence-based. A curriculum was then designed by the researcher based on the recommendations within the literature. Secondly, as it has been suggested that treatment protocols be standardized and replicable (Northam et al., 2005), the program was written with this consideration in mind. Suggestions for adapting aspects of the program across settings and sub-groups of patients, however, was incorporated in order to enhance the potential reach of the program. Thirdly, with regard to conceptualization of the program’s treatment goals, as a meta-analysis suggested that interventions are most likely to be effective if they are delivered with the goal of addressing the multiple aspects of management of T1DM simultaneously, the program was designed to target and evaluate both medical and psychological outcomes (Hampson et al., 2000). In other words, this program aims to impact the most important psychological and behavioral aspects of diabetes management together, rather than simply focus on singular behavioral management factors (such as regular testing of blood glucose, adhering to the prescribed diet, following up with the physician at specified time intervals, etc.). Finally, given the recommendation that goals should be crafted so that influential

people in the adolescents' lives are at least indirectly targeted (Delamater et al., 2001), both family and social-level goals were addressed in the program.

Development of the Proposed Evaluation Measure to be Used in Future Investigation

Drawing upon identified areas of literature described above, the investigator designed an instrument to measure opinions about the program itself as well as clinician attitudes and beliefs about integrated care for use in future studies. Given that the dissertation involved designing a new comprehensive program for a specialized population of patients, no instrument existed that would apply to evaluating all aspects of the program's content and delivery methods. In addition, given that integrated care is a relatively new model of practice and there is a dearth of research on clinician's attitudes and beliefs about the subject, an appropriate pre-validated measurement tool was not readily available for inclusion as a resource in the program. Therefore, the investigator generated a survey using the theoretical constructs outlined in the literature that are of importance for program evaluation (Treasury Board of Canada Secretariat, 1998).

Specific items were generated based on important themes from the literature review—both psychological interventions and clinician knowledge, attitudes, beliefs, and practices. The evaluation tool was guided by several principles outlined by the program evaluation literature, including assessing the program design, plans for implementation, potential outcome or impact, and potential cost-efficiency (Rossi, Lipsey, & Freeman, 2004).

The creation of the survey items was based upon research findings of surveying clinicians (Burns et al., 2008). In total, approximately 50 items were included, the majority of which are assessed on a 5-point Likert scale. Sections of the tool consisted of the following four sections: (a) demographics and professional background; (b) evaluation of proposed program contents; (c) evaluation of proposed program structure; (d) knowledge, attitudes, and beliefs about integrated

health care. Questions assessing demographics had close-ended response choices. There were approximately 1–2 items in the other three sections that ask for an open-ended written response.

To view the survey in its entirety, please see Appendix B.

Chapter 4: Discussion

Clinical Implications of the Program

The developed program, iCAMP T1DM, is a multi-faceted, multi-level, medical clinic-based intervention targeted to adolescents with Type 1 Diabetes Mellitus (T1DM). Given the significant psychological demands of the disease, the goal of the program was to offer evidence-based psychological care to a high-risk group of patients who may not have otherwise been aware of how psychological difficulties impact their medical disease. The main objectives were to reduce the severity of psychological sequelae among this population by intervening both on the individual (adolescent) level and on the level of the family through enhancing knowledge about the link between T1DM and psychological/behavioral factors, reducing mood and behavioral symptoms through cognitive-behavioral approaches, building coping mechanisms for psychosocial and psychological difficulties, including those related to stress-management, family communication, and adjustment, and increasing self-efficacy to effectively battle the many challenges of the disease. T1DM is a very serious illness that will require very careful management throughout the lifetime, and instilling knowledge and skills needed to endure these challenges during such a crucial developmental period is considered to be of utmost importance.

Psychologists are in a unique position to deliver well-validated, appropriate interventions for this population. In fact, psychologists may be one of the most important partners that an adolescent will have in his or her health care, as significant time is dedicated to communication, the therapeutic alliance, and the cultivation of trust. From this standpoint, there is a unique opportunity for psychologists to play a central role in the adolescent's health care attitudes and beliefs in addition to adherence behaviors. Therefore, it is encouraging that recent shifts in the structure of the nation's health care have migrated towards integrated care. It is clear to the field

of psychology that programs that integrate mental health care into routine medical care may be in the position to enhance access to psychological services and offer the preventive approaches that reduce the likelihood of serious future complications of the disease. Including mental health professionals on interdisciplinary teams is an innovative approach that is gaining traction in many settings, and as teams work together in a variety of clinics, additional ways in which care can be delivered effectively in a collaborative fashion will only continue to be realized. However, it is not without its challenges, and the present program sought to identify the difficulties associated with integrated care and offered several reflections and solutions to some of these.

Indeed, despite a current focused effort toward integrating psychological and medical care, there is a lack of existing research on the simultaneous delivery of psychological and medical services for this high-risk medical population. Furthermore, despite much research attention having been paid to identifying the roles of nuanced psychological variables in diabetes outcomes, there is scant literature on how comprehensive programs would be integrated and sustained in medical settings. Although randomized controlled trials suggest that several interventions are well-utilized to reduce psychological stress, mood disorders, and behavioral problems, it will be interesting to uncover whether effectiveness is heightened by offering tailored packages of these interventions. To understand the influence of the setting in which these services are delivered, the impact of the extended duration and relatively high frequency of services offered, and the influence of family involvement in this program will be crucial.

It is the hope that this program proposes principles and guidelines specifically for the psychologist's role in interdisciplinary care to facilitate patient-centered diabetes care. Future research may examine the developed program through more in-depth study to determine the

effectiveness and feasibility of this model from the clinical and provider perspectives.

Psychologists will be challenged to think through ways in which this program and others can be implemented on several complex levels, beyond the clinical and into the broader context of institutions. And of course, it will be extremely important to identify how the target population perceives this program, including how they may understand the program and its relationship to their own goals about managing T1DM, their interest and willingness to participate, and their potential enjoyment of and benefit from the program.

Recommendations for Future Directions: Evaluation of the Program

In future studies, consideration of evaluating the program prior to program implementation may be considered, and the evaluation measure developed as a part of this dissertation can be utilized for this purpose. Broadly, the central goals of evaluation would be to obtain data from key informant clinicians about their opinions of the program itself and of integrated care as a model for delivering psychological services to medically-ill patients. As described in detail below, data obtained through the proposed survey would be primarily quantitative, as most items would be measured on a Likert scale. The opportunity for evaluators to provide written feedback is also included in the survey, however, so qualitative data may also be collected.

Items on the proposed evaluation tool. In brief, the survey developed includes items evaluating the program and measuring professionals' opinions about integrated care, so it is divided into several sections. On this measure, the program itself is evaluated on two primary levels: (a) the relevance of the objectives and the clinical utility of the interventions for the target population; and (b) the proposed delivery of the program, including its potential applicability and

feasibility within the medical setting. The second main dimension of the survey involves items assessing clinician opinions (e.g., knowledge and beliefs) about integrated care models in general.

Demographics and professional background. Demographic characteristics of interest include gender, age group, ethnic/racial identification, and primary professional identification. Professional characteristics of interest include: number of years of professional practice as a clinician (if doctoral-level, such as psychologist or a physician, counting the first year of practice as the first year of the post-doctoral or residency program, respectively); current employment setting; percentage of practice that has involved treatment of children/adolescents, adults, diabetics, patients without insurance or with public insurance, non-native English speakers; extent of and nature of their inter-disciplinary collaboration; familiarity with integrated health care; familiarity and experience with psychological interventions for patients with chronic disease; and familiarity and experience with psychological interventions for pediatric patients with diabetes.

Evaluation of proposed program contents. An abbreviated but detailed description of the program's content areas is provided. Approaches taken in a typical individual or group CBT session is offered. After reading information about the program's rationale and specific intervention arms of the program (i.e., individual CBT treatment, group CBT treatment, family psychotherapy, family psychoeducation, coping skills groups, and assessment), clinicians can be invited to provide their opinions about the programmatic content. Approximately 10 items assess their opinions about the program's objectives, the potential benefit to the population, the efficacy of the interventions selected for inclusion, and the likely outcomes (both physical and psychological) they imagine might emerge after program participation.

Evaluation of proposed program structure. Clinicians are then asked to consider that the program delivers the services described in an integrated health care setting. A definition of integrated health care, according to the American Psychological Association, is provided for their reference. In addition, a graphic depiction of the structure of the program is provided. This flow chart displays the program's conceptualization of inter-disciplinary care and specifically refers to examples of the roles and functions of the psychology team in the model. Clinicians are then asked to provide their opinions about the systemic issues involved in delivering a psychologically-focused program in a medical environment. These items measure the potential appeal and value of the program to patients and clinicians; the potential for the program to be able to identify high-risk patients and provide culturally-responsive care; and the potential to improve health outcomes. An open-ended item is included for the clinicians to state their beliefs about the largest barriers to adoption of a program delivered in this format. This will enable the experts to provide specific comments, recommendations, reservations, and questions about the program.

Knowledge, attitudes, and beliefs about integrated health care. Finally, clinicians are asked for their professional opinions about integrated health care, in general. These items ask evaluators to rate their knowledge about changes in health care reform that involve new collaborative approaches between mental/behavioral and medical providers. It also measures their attitudes about their openness to practice in such an environment, beliefs about such a model might benefit patients with complex healthcare needs, and beliefs about the feasibility of the approach from administrative, professional, and economic perspectives. Clinicians are also provided the opportunity to describe what they believe the impact of integrated health care would be on the future of health services, as well as their concerns about the model.

Suggestions for future use of the evaluation tool. Future studies may choose to use this survey to assess the clinicians. An internet-based survey may be best to facilitate access to the population of interest in a timely manner, may make it possible to reach individuals with certain specified characteristics, may avoid the logistical challenges of arranging for individuals to complete the survey by mail or in person, and is cost-effective (Reips, 2013).

Additionally, it is suggested that future studies gather feedback from a diverse group of practicing clinicians: (a) psychologists employed in medical or hospital settings who are involved in the care (psychotherapeutic or assessment) of medical patients with chronic disease and (b) non-psychologist health care providers (i.e., physicians and physicians in training, nurses, licensed clinical social workers, and diabetes educators) who treat such patients in medical settings. Both psychologists and other health care providers could be considered to evaluate this program given the aims of offering a comprehensive psychological program within a setting where medical providers predominate in terms of the provision of health services.

Target groups of clinicians who could evaluate the program can be defined in various ways. For instance, a clinical psychologist who may provide helpful feedback may have the following characteristics: (a) a licensed clinical psychologist or a post-doctoral fellow in clinical psychology; (b) who currently works in a hospital or outpatient medical clinic setting; (c) who has at least 2 years of professional experience in the treatment of patients with medical conditions (can include post-doctoral training); (d) who has at least 1 year of professional experience in providing psychological care for children and/or adolescents (can include post-doctoral fellow training); and (e) has at professional experience evaluating or treating at least one diabetic patient in therapy or through consultative work (can include post-doctoral fellow training). A physician target group could be defined as follows: (a) a licensed physician or

resident physician currently practicing in pediatric endocrinology, pediatrics, family medicine, or endocrinology; (b) who has had specialized training or professional experience in the treatment of pediatric patients with diabetes mellitus; and (c) who is currently employed in a setting where they have ever collaborated with mental health care providers in their care of patients (i.e., where they are practicing in an institution where any psychologists, social workers, nurses, masters-level psychotherapists can share patient-care responsibilities, either through psychotherapy or consultation/liaison services). Finally, a target group of ancillary health care providers could be defined as follows: (a) either a licensed nurse, licensed clinical social worker, masters-level psychotherapist, or diabetes educator; (b) who is currently involved in the treatment of patients with diabetes mellitus; (c) who is currently employed in a setting where they have ever collaborated with mental health care providers in their care of patients; and (d) who has experience in treating pediatric patients with diabetes.

Suggestions for recruitment of clinician evaluators in future studies. There are several ways in which the recruitment of study participants could take place. First, a purposive sampling method could be considered, as it is a common approach for studies attempting to collect pilot data on whether a new type of program would be seen as potentially valuable by the professional community (Bernard, 2000). In purposive sampling, participants are targeted for participation based on the investigator's judgment that their sets of professional experiences are a good fit for the participation in the research (Chaudhuri & Stenger, 2005). In future study using the proposed measure, it may be helpful to recruit target evaluators who possess specialized experience and expertise in the areas of diabetes mellitus, pediatric psychology, and/or multi-disciplinary approaches to patient care. Therefore, purposive sampling may be a viable sampling technique to obtain information from the very specific and limited pool of people that have these

professional characteristics. Indeed, the sampling technique has been utilized in studies assessing clinician knowledge and practices (Dawes & Sampson, 2003; Shelley et al., 2009).

Furthermore, a future investigation may wish to recruit clinicians who practice at university-affiliated medical centers and/or children's hospitals that utilize either multi-disciplinary team approaches to pediatric care or house programs geared toward T1DM pediatric patients. Moreover, psychologists employed in these university or university-affiliated hospital settings may also have familiarity with recent advances in evidence-based psychological treatments for chronic disease patients. In addition, targeting clinicians from children's hospitals may result in a sample of participants that currently treat a high volume of pediatric patients, yielding an experienced sample. The purposive sampling method, in this case, could facilitate greatest accessibility to clinicians who may meet target evaluator requirements.

As a secondary means of recruitment, the snowball sampling method may also be considered in future investigation. This sampling method is also utilized for studies with a sample that is limited to a small subgroup of professionals (Bryman, 2012). Snowball sampling involves asking initial participants to identify other potential participants who also meet the criteria for a target evaluator but who may be difficult to locate (Sadler, Lee, Seung-Hwan, & Fullerton, 2010). Although this method potentially creates a sample where participants may disproportionately share similar traits and characteristics by virtue of being professionally affiliated, it may broaden the sample pool to participants who live outside of particular metropolitan areas, contributing to geographic diversity in the sample. The geography diversity factor is of interest given that financial reimbursement structures for integrated care programs may differ by state, which may impact clinician opinions on the program. Therefore, utilizing

snowball sampling as a secondary recruitment method may further facilitate access to experienced clinicians.

It is noted that the primary sampling method, purposive sampling, and the secondary method, snowball sampling, are non-probability sampling techniques (i.e., where not all clinicians in the target population have equal chances of being selected), which carries its limitations. However, the evaluation tool may be used to document particular beliefs and characteristics that occur within the clinician sample, and the descriptive study design is useful for pilot studies and obtaining basic descriptive data and trends. Future studies may also utilize probability sampling (randomized approaches) in order to conduct inferential analyses about the program and trends within the target population.

Suggestions for study design and analysis utilizing the evaluation measure in future studies. The evaluation measure can be used in a future descriptive study. This study design is efficient and useful for investigations of narrowly-defined clinician types and treatment approaches that may be less common among particular populations (i.e., clinical psychologists with experience in treating chronic medical disease in multi-disciplinary settings). Descriptive research can be particularly valuable in the stage of program design and development as in this study. It is a useful design for exploratory research to document feedback about how to refine the proposed program's objectives, strategies, and activities as well as to generate hypotheses and identify potential areas of research for future investigation (Grimes & Schulz, 2002; Kelley, Clark, Brown, & Sitzia, 2003). Survey methods are often used to gather descriptive data to inform future revisions and guide implementation of the program (Jackson, 2009). The research design lends itself to analysis using descriptive statistics that will help describe basic opinions and trends.

Although a potential pitfall of this study type is that it has lower levels of external validity and is more prone to biases, the design will hopefully lend itself to exploration of new ideas and concepts in the pediatric psychology literature. The design may be useful in efficiently gathering preliminary data (specific suggestions from a diverse pool of clinicians) that would lead to the refining and revising of the program for future study.

Additional future investigations can be carried out using probability sampling and randomized approaches in order to expand the inference about the entire target population of clinicians. Randomized sampling may result in a sample that more accurately reflects the whole host of characteristics of the population of interest, professionals who care for T1DM adolescents. Sampling error resulting from a small sample size, nonrandom participant recruitment, and selection bias may be less likely in this approach. However, selection bias may still be present in any study, potentially resulting in an over-representation of individuals who have greater knowledge about current trends in integrated care programs, who are more motivated to respond, who have fewer personal or professional time constraints, or who have stronger opinions about the subject.

Care to sample a diverse pool of various professionals who have experience treating diabetic patients and who have familiarity with multi-disciplinary approaches to health care should be taken. This would help to gather as diverse viewpoints as possible given the format and goals of the program. However, there is always a possibility that recruiting a wide spectrum of professions may create a biased sample, in that health care professionals who are less familiar with specific psychological interventions (e.g., nurses, diabetes educators) would be asked to provide their opinions on several specific psychotherapeutic modalities in a segment of the survey. Therefore, it is possible that a limited range of clinician subgroups would participate in

the survey, creating a disproportionate sample, and this would need to be attended to in the design and analysis phases (e.g., statistical corrections may be possible in the data analysis stage should there be an under-representation of the psychologist strata). If, however, the degree of under-representation of psychologists is small, the sample may be treated as a reasonable approximation to a random sample of clinicians with the specified characteristics.

A random sample may enhance the external validity of the findings. In other words, the data collected may be an approximate representation of the opinions of psychologists and health care providers about the T1DM program and integrated care. In addition, a study design involving surveying clinicians via a self-report measure is less likely to create additional forms of bias, including information or observation bias (e.g., interviewer bias).

It is the hope that any data gathered in future studies will help guide any future programming planning and/or implementation efforts with diabetic adolescent patients.

Conclusion

The program was developed to guide clinicians and program planners to implement interventions to help reduce the morbidity caused by psychological struggles with diabetes mellitus. In this dissertation, a comprehensive program, based on an extensive review of the literature of the relationship between T1DM and psychological functioning in adolescents, was developed. The program presented key information about the target population, the statement of need, the main objectives, and the strategies for implementation and evaluation. It was important to disseminate guiding principles of how to adequately address the most pressing needs of adolescents with diabetes. Close attention was paid to increasing the understanding of T1DM, modifying attitudes and beliefs about the disease, and empowering adolescents and their families to adhere to prescribed regimens in an effort to maintain glycemic control and psychological

well-being (in the short-term) and to prevent significant complications and potentially psychopathology (in the long-term).

In addition, efforts were made to highlight the crucial role of evaluation in such a program, and survey research tactics were proposed. Developing additional evaluation measures about the program itself is a crucial next step in order to refine the program, streamline its approaches, and ensure that its interventions are palatable and valuable to the adolescents. It is the hope that the program and its framework can serve as an effective tool and roadmap for implementing the most efficacious interventions to serve a highly-deserving population of patients.

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APPENDIX A
Program Handbook

GUIDEBOOK FOR PROGRAM
IMPLEMENTATION

iCAMP T1DM

Integrated Clinical Assessment &
Management Program
for Type 1 Diabetes Mellitus

Designed to promote the psychological well-being of
Type 1 diabetic adolescents

Created by

Stephanie R. Young, M.P.H.

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Chapter I: Executive Summary

The iCAMP T1DM program is a multi-faceted, multi-level, medical clinic-based intervention targeted to adolescents with Type 1 Diabetes Mellitus (T1DM). The goal is to improve psychological and diabetes-related health through the delivery of an integrated care program specifically designed for a high-risk population of T1DM patients, adolescents. One objective of the program is to reduce the severity of psychological sequelae among this population. Other objectives are to increase patients' knowledge about T1DM (including how their psychological and behavioral functioning affects their medical outcomes), to build coping mechanisms for psychosocial and psychological difficulties, and to improve their perceived level of social support and self-efficacy to effectively battle challenges of T1DM.

The program is designed to address the psychological care of T1DM adolescents, and is formatted for integration into the tertiary medical clinic setting (such as the pediatric endocrinology clinic). Prior empirical research has identified specific components of interventions that have been shown to impact adolescents' psychological functioning and T1DM outcomes. These include aspects of cognitive-behavioral therapy, coping skills training, and stress management, for instance. The most efficacious programmatic elements were identified for use in this program, and the program content has been designed to be delivered into the medical clinic in an effective and feasible manner. This program is uniquely designed for

implementation in an integrated care context, where patients are treated by an interdisciplinary team of professionals.

Integration of mental and physical health services is critical in this population, as is often said that the psychological demands associated with the management of diabetes are as significant and extensive as the medical ones. In diabetes, integrated care is thought to enhance health outcomes, expand access to appropriate treatment, increase convenience of receiving services for the patients and their families, and reduce the stigma associated with seeking psychological care.

This program proposes a new model of care adapted to the pediatric endocrinology clinic, where most T1DM diabetics receive routine services. It delineates the roles and functions of the psychologists (and other professionals), the collaborative processes, and the clinical care strategies in detail. In effect, it proposes principles and guidelines specifically for the psychologist's role in interdisciplinary care to facilitate patient-centered diabetes care.

Evaluation of iCAMP T1DM will consist of commonly-used pre-test and post-test measures of T1DM outcome measures as well as psychological symptom severity; self-efficacy; diabetes-specific knowledge, attitudes, beliefs; and management behaviors.

Chapter II: Problem Statement

Type 1 Diabetes Mellitus (T1DM) is an autoimmune disease that is characterized by failure of pancreatic beta cells to produce insulin, the peptide hormone that regulates glucose metabolism. Without insulin, glucose levels in the blood and urine rise (hyperglycemia), causing symptoms of polydipsia, polyuria, and weight loss. Type 1 diabetics depend upon exogenous insulin replacement for survival, either through wearing an insulin pump or through multiple direct injections of insulin daily. The goal is to maintain control of glucose levels within the normal range of 70–130 mg/dL, but episodes of hypoglycemia are very common in T1DM patients.

Current insulin therapy has transformed T1DM from a once fatal disease to a chronic illness. However, even with daily management of blood glucose levels, there are both short- and long-term complications that can arise. In the short term, excessively high blood glucose levels lead to hyperglycemia, which can result in diabetic ketoacidosis (DKA), a life-threatening condition, or a diabetic coma. Short-term effects of unrecognized hypoglycemia, excessively low blood glucose levels, include loss of consciousness, seizures, or even death. Over time, persistent or untreated hyperglycemia produces serious organ damage, particularly in the nerves and the microvasculature of the eyes, kidneys, and heart, resulting in retinopathy, neuropathy, and cardiac events. Maintaining tight glycemic control may delay the onset of and/or minimize the impact of complications, but type 1 diabetics have a shorter life expectancy and typically die of renal failure or cardiac disease. Thus, it

is crucial that the type 1 diabetic consistently attend to the management of the disease.

Usually diagnosed in childhood or adolescence, T1DM affects between one million and three million people living in the United States. It accounts for approximately five to ten percent of the approximately 26 million total cases of diabetes. Diabetes (type 1 or type 2) is among the most common childhood chronic diseases, and affects about one in 400 children and adolescents. Approximately 15,000 American children and adolescents are diagnosed with T1DM each year. There is evidence to suggest that the incidence of T1DM among youth worldwide is increasing rapidly at a rate of approximately three percent per year, creating a pressing global public health problem, especially among the youngest children.

Type 1 diabetes mellitus (T1DM) requires a complex and arduous daily management regimen. The disease can present dramatic changes in daily life, placing a significant psychological burden on the patient, particularly in childhood and adolescence. Behavioral and psychological factors can significantly influence the course and progression of T1DM. These interactions are bidirectional—metabolic and biological fluctuations produce alterations in emotions and behaviors, and psychological functioning predicts glycemic control and other medical outcomes.

Several of the central psychological predictors of T1DM health outcomes are listed below:

1. **Stress:** Psychological stress, whether it is acute or chronic, can create disturbances in a child's glucose metabolism. Poor adherence is thought to be a major result of stress, and it may also be triggered by worsening glycemic control.
2. **Coping:** Certain coping styles, such as those involving avoidance, help-seeking, or wishful-thinking, lead to poorer glycemic control.
3. **Poor medical adherence:** May be due to stress, cognitions about diabetes, behavioral problems, family communication difficulties, or any mood issue. This is thought to be among the most frequent presenting problems and can pose the most deleterious effects on medical outcomes.
4. **Illness perceptions:** Whether a child adheres to adaptive and healthy behaviors depends on several factors involving perception of the threat that the illness poses, potential benefits and costs of managing the illness, and cues to engage in treatment behaviors, according to the Health Belief Model. There is evidence that youth may perceive greater threat for short-term complications such as hypoglycemia and hyperglycemia, but perceive lesser severity and susceptibility related to long-term consequences (e.g., kidney disease, neuropathy) due to a lack of cognitive maturity. The youth generally believe they themselves have less of a chance of experiencing long-term complications compared to others. This can lead to adolescents not adhering strongly to insulin, diet, and exercise recommendations.

5. **Adjustment:** In the aftermath of the T1DM diagnosis, it is not uncommon for the child to experience sadness, social withdrawal, and anxiety. Other adjustment-related problems include passivity and unhealthy reliance on the parents for managing the treatment regimen.

6. **Psychiatric diagnoses:** The most prevalent diagnoses include depression, anxiety, and eating disorders. Externalizing/behavioral disorders are also represented in this population, to a smaller degree. Psychiatric disorders are associated with a greater frequency of hypoglycemia and hyperglycemia as well as diabetic ketoacidosis. Depression in T1DM children, for instance, is often precipitated by feelings of loss of motivation, anhedonia, and hopelessness related to managing the diabetes. The presence of family conflict can reduce feelings of support within youth, increasing sadness and stress; peer relationships and peer pressure within the context of forming an identity also influence risk for depression.
 - a. **Depression:** approximately 25% of T1DM adolescents.

 - b. **Anxiety disorders:** approximately 10-20% of the T1DM population

 - c. **Disruptive behavioral disorders:** approximately 10-20% of the T1DM population

 - d. **Eating disorders:** approximately 8–30% of T1DM adolescents

7. **Family influences:** Family cohesion, level of supportiveness, warmth, nurturing, amount of collaborative problem-solving, understanding, as well as degree of conflict have a substantial impact on the management of a T1DM

child. In general, highly-supported T1DM youth—in that parents are involved in management—have better regimen adherence and outcomes. When responsibilities given by parents are developmentally appropriate and tailored to the child's psychological maturity, treatment adherence is better and there are fewer dangerous complications requiring hospitalization.

8. **Parental adjustment:** Parents carry a burden of caring for their child, which significantly increases stress. In fact, such stress seems to create greater risk for psychological problems for mothers after their child is diagnosed; problems tend to be depression (in approximately one-third of mothers), and PTSD (in nearly one-fourth of mothers and one-fifth of fathers six weeks after diagnosis). Parents worry greatly about possibilities of hypoglycemic and hyperglycemic episodes in addition to changes in routines of their children that can precipitate these. Coping strategies of parents, such as their willingness to be knowledgeable about the disease, their degree of communication with professionals, seem to relate to their child's health outcomes as well.
9. **Poor academic functioning:** Academic weaknesses, such as poor mathematics or reading skills, can directly impact the adolescent's ability to calculate insulin dosing or carbohydrates in foods. Learning disabilities or ADHD may also directly affect management. From a neuropsychological standpoint, there is evidence to suggest that diabetics may perform worse on measures of attention and executive functioning.

Given the substantial evidence of the extent to which psychological and behavioral factors interact with T1DM, the program will seek to intervene on the major psychological risk factors at multiple levels (patient and family) in a setting where mental and physical health is simultaneously addressed.

Chapter III: Target Population

A particularly high-risk group within the T1DM patient population is adolescents. Given the critical biological, cognitive, emotional, and social changes that occur during adolescence, glycemic control typically diminishes. T1DM can also increase the adolescent's risk for psychiatric illness and can contribute to decreased self-esteem, conflict with family, peer difficulties, and poor coping with illness demands. Therefore, this program targets adolescent T1DM patients who are currently receiving healthcare at their specialty medical clinic (pediatric endocrinology). Because patients are already receiving care at the medical center, this program is designed to provide services in the same clinic to enhance coordination of care and reduce the stigma of receiving mental health services.

The program targets adolescents given the many changes that occur in this developmental period that put patients at higher risk for medical complications and psychological problems. Adolescence, a developmental stage that involves solidifying one's identity and a degree of parental separation, poses manifold challenges and stressors for the T1DM patient. Diabetes affects child-parent relationships, quality of life, school or work difficulties, and involves having to respond and adapt to the disease within the context of identity establishment.

From a cognitive development standpoint, the greater use of hypothetical and deductive reasoning in adolescence may create negative emotional reactions as adolescents consider the potential future complications and challenges of T1DM. A

deeper understanding of the illness coupled with a low self-efficacy to modify or control the inevitable complications may be very worrisome for the patient. From an interpersonal relationship perspective, adolescents begin to establish autonomy from his or her parents, who may be highly involved in daily management. This can be stressful and can represent a major source of family tension, resentment, or conflict. Furthermore, adolescents may be more vulnerable to peer pressure, and there is evidence to suggest that adherence behaviors decrease during this period secondary to wishing to gain peer approval or being self-conscious about feeling “different” from peers. Thirdly, multiple transitions take place in the adolescents’ schedules, which can be disruptive to routines for adherence. With more extracurricular activities and time spent outside the home, the responsibility of care must shift from the parent to the child for the first time. In addition, these lifestyle changes can lead to unpredictability about how activities and physical exercise will affect blood glucose levels. Finally, the hormonal changes caused by puberty have direct effects on glucose metabolism and regulation. The onset of puberty poses the biggest challenge for the adolescent, as he or she is experiencing frequent and more intense glycemic fluctuations for the first time.

Importantly, there is substantial evidence that adolescence creates a risk for reduced glycemic control. A major research study, the Diabetes Control and Complications Trial (DCCT), demonstrated that HbA_{1c} levels (a glycemic control biomarker; representative of mean blood glucose over the past three months) are significantly higher in the adolescent cohort compared to adult cohorts. Specifically, HbA_{1c} levels were often greater than 8.0% (for reference, the normal range for the

HbA_{1c} test is 4.8–5.9% in non-diabetic individuals; the recommended HbA_{1c} target is below 7.0% for adult patients and below 7.5% for adolescents). Additionally, there was a two- to four-fold increase in hypoglycemic risk compared to other age groups. In a major cross-sectional study of children and adolescents with T1DM from 18 countries in Europe, Asia, and North America, similar results regarding glycemic control were reported. Mortensen et al. (1998) discovered that while mean HbA_{1c} in children younger than 11 years was 8.3%, adolescents between the ages of 12 and 18 had a mean HbA_{1c} of 8.9% (and 41% of children had an HbA_{1c} below 8%, while only 29% of adolescents did). This result was especially interesting as the adolescents received insulin three times (as opposed to only twice) daily. The authors found that these findings persisted even when given more daily injections, and therefore concluded that non-biological variables such as psychological states and behaviors may be as important as injection frequency and dose in achieving good glycemic control.

Therefore, the program is designed to identify at-risk adolescents early so that potentially beneficial effects on their medical and psychological outcomes can be rendered through participation. The interventions selected for inclusion in the program have all been recognized as effective for treating T1DM adolescents' presenting psychological and behavioral difficulties. The program focuses on cognitive-behavioral therapeutic interventions, which have been found to reduce symptoms and severity of common mood issues in this population. Furthermore, the program incorporates elements of family psychoeducation and psychotherapy, which can offer further protective effects.

Chapter IV: Preparing for Program Implementation

PROGRAM RATIONALE

Managing diabetes mellitus can be extraordinarily complex. Healthy management of the disease, in many ways, depends upon continuity of health care services to achieve optimal management. This is especially true for adolescent patients, who undergo multiple developmental transitions that can contribute to the challenge of maintaining good glycemic control. There are multiple psychological sequelae of type 1 diabetes that can present particular challenges to this high-risk group of patients.

This program has been designed to enhance psychological well-being and behavioral management in adolescents. Understanding, approaching, and treating the psychological and behavioral facets of the disease, whether it is depression, stress, anxiety, poor academic functioning, disordered eating, or PTSD—helps to optimize patients' psychological and medical outcomes. Because of the close association between psychological functioning and medical outcomes, the program has been designed for implementation in the medical setting.

Positioning a psychological program within the medical clinic enhances coordination between medical and psychological care and creates more efficient access to services. This approach, called integrated care, has been shown to result in reduction of health care utilization costs and improved treatment outcomes in diverse patient populations. This is due, in large part, to the fact that integrated care

models historically emphasize disease prevention and wellness promotion. In the context of diabetes, it is thought that integrated delivery approaches can decrease medical costs associated with health care utilization (e.g., the costs of hospitalizations, diabetic ketoacidosis episodes).

With the support of literature, which suggests that the creation of a “customized package” of efficacious psychological interventions, tailored to a particular population’s needs and goals, would best optimize medical and psychological outcomes, this program was developed. The program’s main objective is to build in pre-validated programmatic elements that can align and synergize in a fashion that results in the greatest potential for improved health outcomes in adolescents with T1DM.

PROGRAM OBJECTIVES

There are two main categories of goals in this program: patient-level goals and program-level goals.

I. Patient-level goals: *The direct goal* is to improve the most prevalent behavioral and psychological problems experienced by T1DM adolescents. *The indirect goal* is to improve medical outcomes (targeting psychological functioning will then indirectly contribute to improved physical health outcomes). The selected interventions are aimed at having direct effects on the specific psychological and behavioral variables shown to reliably predict glycemic status. The central program goals are listed as follows.

1. Facilitate the adjustment to the T1DM diagnosis
2. Reduce psychological sequelae of diabetes (e.g., depression, anxiety)
3. Enhance coping skills
4. Improve family communication
5. Increase use of problem-solving skills
6. Increase use of benefit-finding
7. Enhance perceived health-related quality of life
8. Improve adherence to medical regimen

In general, treatments that have been identified as the most efficacious in the literature tended to be those that specifically targeted *psychological outcomes* compared to targeting glycemic control itself (Plante & Lobato, 2008). However,

other research has argued that targeting adherence (a *behavioral outcome*) and glycemic control is equally important (Harris et al., 2010). There is research that indicates that focusing on psychological outcomes is likely to provide a more long-lasting change on the patient and his or her family, as changes in glycemic control may be observed later on (Harris, Freeman, & Duke, 2010).

Therefore, in an effort to optimize the chance of improving psychological and medical outcomes, this program is designed to address both psychological (e.g., depression) and behavioral (e.g., adherence) goals.

II. Program-level goals: These are designed to address how the program itself will be delivered in the integrated care context. These include the logistical goals of integrating the psychological services within the medical clinic, partnering with non-psychology staff, and financing the clinic. It should be noted that the program assumes that the senior leadership within the institution in which the program is to housed is supportive of integrated behavioral health approaches to care, and there is an administrative infrastructure that allows for achieving integrated care within an outpatient clinic.

A psychologist implementing this program should attend to the goals below prior to program implementation.

1. Clarify how psychologists will be integrated into the medical clinic
 - a. Identify the role and responsibilities of the psychologist in this setting
 - i. Brief, one-time interventions
 - ii. Longer-term intensive psychotherapy services

- iii. Psychodiagnostic and/or neuropsychological assessment
- iv. Group psychotherapy
- v. Provision of psychotherapy and assessment services to patients
- vi. Provision of caregiving and coping-oriented services to families

Of note, pediatric psychologists have been successful in establishing and integrating themselves into comprehensive centers treating pediatric T1DM patients (Anderson, Loughlin, Goldberg, & Laffel, 2001).

2. Specify how psychology care will be delivered in the clinic

a. Determine the space required

Individual and small-group (including family) level interventions are well-suited for integration in the clinic setting, in terms of requiring small and simple spaces without special equipment.

b. Ensure that psychological services are coordinated with medical visits

This is thought to likely enhance access and reach (Harris et al., 2010). Furthermore, group-level interventions are already a well-established modality of therapy in psychiatric clinics in hospitals.

3. Develop a partnership and plan for collaboration with members of the medical treatment team

- a. Ensure that psychologists may develop thorough knowledge about T1DM, including its etiology, diagnosis, treatment, and course, so that communication with other providers is most effective.

This is an important way in which psychologists can demonstrate their value to the medical team (Wysocki, 2006).

- b. Specify the ways in which psychologist-medical provider communication will take place (via warm hand-offs, medical records, integrated team meeting, specified time slots during integrated clinics)
 - c. Ensure that plan for billing for care is addressed in advance
 - i. Utilize Health and Behavior Codes to optimize reimbursement process. Recommendations for using these codes in pediatric programs are readily available through the American Psychological Association Division 54 website, which should be consulted for the most recent information. In brief, Health and Behavior Codes can be by non-physician providers to bill for psychoeducation or health behavior coaching at the individual or group level, psychotherapy, assessment, and care management/coordination.
4. Provide opportunity for training of future psychologists
- a. Build a psychology practicum position into the program
 - b. Build an elective for a psychology post-doctoral fellow into the program

In addition to the specialized educational opportunity for trainees, studies have shown that including training initiatives within the clinic-integrated program can help to reduce any potential barriers to financing the program (Kazak et al., 2007).

5. Delineate another essential role of the psychologist on the medical team: a consult to the providers

One of the most important and unique roles of a psychologist working on a multi-disciplinary team is that of the consultant to the medical team. In this capacity, the psychologist provides guidance to health care colleagues (physicians, nurses, diabetes educators) and addresses specific questions that arise both in the clinical management of patients and in the context of working in a multi-disciplinary team. The psychologist is uniquely suited to assist other providers in understanding nuances of a patient's presentation and can help communicate strategies to problem-solve around difficulties to the other treating providers in a constructive and collaborative fashion. For instance, a psychologist may respond to questions about how to collaboratively interact with patients and families, set boundaries, manage behavioral issues, and understand psychological issues that emerge while treating the patients. In addition, the psychologist can address ways in which team members can best communicate with other providers and can assist in managing the group dynamics that often arise in team meetings. In addition, they may encourage and support providers' own self-care and stress-management in order to best facilitate direct patient care. In fact, it is important to bear mind that in integrated care, one of the most central roles for psychologists may be to provide education to other providers, informally through recommendations in the clinic, as well as through structured courses on medical units. In effect, psychologists are skilled to meet the needs of two different pools of consumers: patients and providers, and both are viewed as highly valuable contributions within the integrated care environment.

PROGRAM STRENGTHS

- Focuses on a prevalent childhood disease that often is treated primarily from a medical model, but also has potentially significant psychological effects that can worsen the disease
- Integrated into the medical clinic, which can decrease stigma associated with seeking psychological care, increase access, enhance credibility, ensure that interventions selected are relevant and timely, and increase continuity of care
- Empirically-supported CBT approaches utilized
- Program interventions blend features of didactic lessons with elements encouraging self-efficacy and social support
- Emphasis on prevention, as providing psychoeducation, therapy, and parental support can impact future mental health of patients (as well as impact mental health and the functioning on the level of the family)
- Program designed to generalize to diverse patient settings, particularly clinics where training programs are incorporated; this can help ease financing the clinic
- Program builds upon models that have worked effectively across ethnically-diverse patient populations
- The peer support element will allow the opportunity to create informal social networks through which T1DM patients and their families can maintain contact
- Emphasis on program evaluation (both outcome and process evaluation)

PROGRAM LIMITATIONS & BARRIERS TO CARE

- Potential high rates of attrition, given the level of commitment required in the program
 - To address the high attrition rates, it is suggested that incentives for the patients to continue to attend clinic are considered (e.g., certificates when modules are completed, small gifts or snacks)
- Transportation issues may affect attendance to sessions
 - It is recommended that the program determine whether public transportation to the clinic is an option in their area
- T1DM adolescents and their families may perceive certain modules as too long a commitment
 - Monthly booster sessions can be implemented in case patients are unable to attend sessions as regularly as they would like to

Chapter V: Program Implementation Guide

ADMINISTRATIVE CONSIDERATIONS

It should be noted that this program assumes that the senior leadership within the institution in which the program is housed is supportive of integrated behavioral health approaches to care and there is an administrative infrastructure that allows for achieving integrated care within an outpatient clinic.

The program's structure draws upon the general recommendations of Glasgow and Eakins (2000) for developing integrated care models of care, as well as various guidelines from clinical trials of integrated psychological interventions within T1DM youth.

RECRUITMENT OF PATIENTS

The program targets T1DM adolescents. In this program, adolescence is defined as ages 11–18.

Two groups of patients are selected for inclusion into the program:

1. Newly-diagnosed adolescents
2. Adolescent patients who have an established diagnosis from pre-adolescence and who are receiving ongoing medical care in the medical (i.e., pediatric endocrinology) clinic.

OVERVIEW OF THE STRUCTURE OF THE PROGRAM

The major stages of the program through which the T1DM adolescent will progress through the program, from recruitment to termination, are now addressed. In brief, first, the patients will be identified as potential enrollees and then will be triaged to different intervention routes depending on their level of risk for psychological and/or behavioral problems. They will then become official program participants once triaged, and throughout their participation, will be evaluated for psychological, behavioral, and medical outcomes.

The program aims to offer a highly specialized team of health care professionals to treat the T1DM adolescent in a clinic committed to multi-disciplinary approaches. The approach of the program is to offer consultation only or consultation and treatment to the adolescent and the family, depending on the nature of their presenting issues.

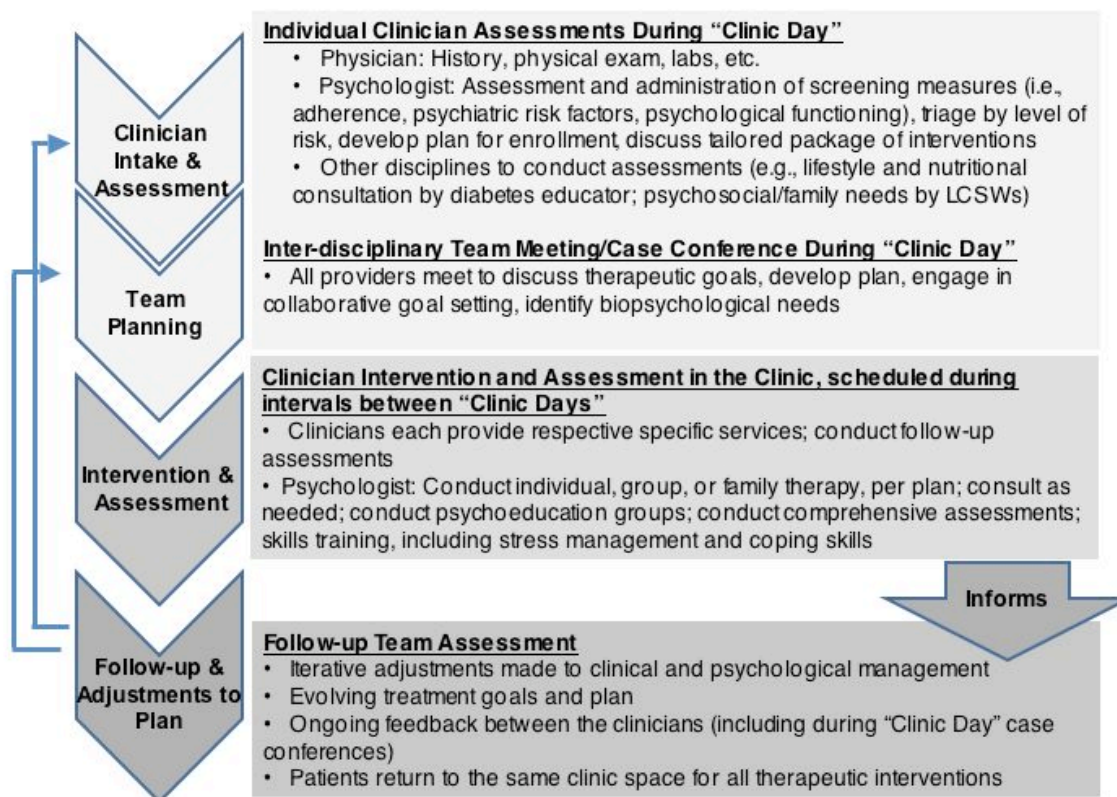
Once enrolled, the adolescents will be seen in the medical clinic, both for “shared” visits during “Clinic Day” and for the “psychologist-only” visits during the intervals between “Clinic Days.”

- **Clinic Day:** This involves the patient being assessed by multiple disciplines during an extended “shared” visit. During this visit, the physician performs the physical exam, orders necessary labs and tests, and evaluates the medical history. The psychologist administers screening measures, evaluates the current level of risk (from a psychological functioning standpoint), and either

creates or monitors the tailored package of interventions (depending on whether it is the patient's first Clinic Day visit or if it is a follow-up visit). Other disciplines, including diabetes education and social work, also perform their assessments of the patient. Importantly, the inter-disciplinary team meeting takes place on this day in order to inform treatment planning.

- **Psychology Services:** These take place during the intervals between inter-disciplinary "Clinic Days." Depending on the customized package of interventions selected for the patient, individual, group, or family therapy services are provided.

GRAPHICAL DEPICTION OF CORE ELEMENTS OF THE PROGRAM



During a patient's first "Clinic Day," it entails the following procedures: the physician performs the physical examination in the exam room, the psychologist completes a consultation in the exam room, and other disciplines conduct their initial assessments. The psychologist conducts a detailed assessment of level of risk and capacity to benefit from psychological services, the development of the plan for enrollment in the program and the discussion of appropriate treatments recommended (i.e., comprehensive psychodiagnostic or neuropsychological assessment; group modules of CBT or social skills; individual psychotherapy within the clinic; family psychotherapy within the clinic), and the collaborative development of the follow-up evaluation and care plan.

FREQUENCY AND DURATION OF PROGRAM SERVICES

Once adolescents are enrolled, psychological services are provided on a weekly or bi-weekly basis, depending on the need, and then the participants will be followed by the multi-disciplinary team for a comprehensive evaluation during “Clinic Day” at regular intervals (that may be every 2 months, for instance, depending on the setting in which this program is implemented). It is suggested that psychological services are delivered in the after-school hours.

In addition to the team meetings held during “Clinic Day,” in order to ensure continuity of care and optimize communication across treating providers, the program also suggests that providers arrange a standing meeting on a bi-monthly basis to review patient updates and treatment planning.

With regard to the proposed duration of the program, the patient would be enrolled in one or more arms of the program as long as is recommended by the multi-disciplinary treatment team (based at least in part upon follow-up measures of psychological/behavioral symptoms and glycemic control).

Depending upon the recommendations of the team and the adolescent’s interest, each patient would theoretically be eligible to continue to receive services according to their insurance benefits up through age 18, at which time their care

would be transferred to an adult endocrinology clinic and they would be provided referrals for continued psychological services if necessary.

STAFFING OF PROGRAM SERVICES

Treatment Team: Patients are referred to an inter-professional treatment team for evaluation and treatment of both physical and mental health needs. This team ideally consists of:

- Clinical Psychologists
- Physicians
- Diabetes Educators
- Social Workers
- Nurses
- Dieticians

Treatment Team Roles: During the comprehensive clinic aspect of the program, embedded is the case conference, intended to be held during the final hour of each clinic. This case conference involves all of the treating psychologists, physicians, nurses, social workers, and diabetes educators, and its purpose is to discuss new patients' presenting issues and the updates and progress of the current patients.

The entire treatment team is involved in a patient's initial evaluation in order to clarify the diagnostic and treatment issues.

Clinics would be staffed according to demand, and per volume of the particular clinic. The comprehensive clinic will ideally have one or two licensed clinical psychologists (along with their trainees, whether they are graduate or post-doctoral level) present in order to execute the multiple treatment arms of the program.

DETAILED PROGRAM PROCEDURES

The steps for enrollment and participation in the program are now provided in detail.

I. MEDICAL VISIT (VISIT ONE)

For the newly-diagnosed adolescent patients, once referred to the pediatric endocrinology clinic (from pediatrics, for example), the physician evaluates the patient in a first visit (consult) appointment and begins the medical management of the patient's illness.

- a. Physician introduces patient to the various roles of multidisciplinary team, including the psychologist and the behavioral/mental health team within the "Clinic Day"
- b. Physician briefly explains the purpose of psychological care for all patients, and states that all newly-diagnosed patients are recommended to have a brief meeting with a member of the psychological services team within this visit.

II. WARM HANDOFF TO THE PSYCHOLOGIST (VISIT ONE)

After the physician assessment and exam, the physician consults with the psychologist.

- a. Physician brings in the psychologist (and/or the psychology trainee) to introduce him or her to the patient
- b. Psychologist has an approximately 15- to 30-minute visit with the patient, conducting a brief verbal assessment of the patient with the patient's family present in order to identify any particularly high-risk issues at the point of care. Interview questions can include the following topics:
 - i. Immediate danger issues
 - ii. Significant adjustment difficulties
 - iii. On-going psychiatric issues (depression, anxiety, eating disordered behaviors, externalizing behaviors)
 - iv. Shame or embarrassment regarding the diagnosis
 - v. Perception of cause of diabetes and illness representations
 - vi. Adherence behaviors
 - vii. Recent hypoglycemic events
 - viii. Responsibility for management of T1DM
 - ix. Understanding/insight about medical regimen
 - x. Family tension/conflict

- xi. Current emotional functioning and coping skills
 - xii. Current academic functioning
 - xiii. Current behavioral functioning
 - xiv. Current social/interpersonal functioning
 - xv. Current cognitive issues (attentional fluctuations, memory difficulties, etc.)
 - xvi. Changes from pre-morbid behavior (emotional/behavioral changes observed prior to the diagnosis, or only thereafter?)
- c. Psychologist explains the opportunities for tailored psychological and behavioral care within the clinic, including the various treatments within the clinic
- d. Psychologist develops a plan for enrollment in collaboration with the patient and their family members
- a. Ensure that questions are asked related to how the child's diagnosis affects the family system, including caregiver burden. This will help in gaining understanding of the sociocultural and family factors that may be impacting the adolescent's care.

III. PATIENT COMPLETES PACKET OF MEASURES IN THE WAITING AREA (VISIT ONE)

All patients are asked to complete an intake packet following the visit. Although the psychologist will have determined, from the clinical interview, the likely category of "risk" the patient will be triaged into, should the patient enroll,

this helps to refine the category of risk and capacity to benefit from psychological services. Clinical judgment is used to determine level of risk, along with the guidelines mentioned below.

- a. Psychologist can review the packet in detail after the conclusion of the appointment and alter the category of risk, if appropriate

IV. TRIAGE OF PATIENT BY RISK LEVEL (VISIT ONE)

The triage process is designed as follows. Risk levels are included as a guideline, but psychologists should use careful clinical judgment in their decision-making processes. Importantly, informed consent should be obtained prior to the rendering of psychological or assessment services.

A. "LOW RISK" PATIENTS DESCRIPTION:

- Generally high-functioning
- Would benefit from attention to the most common difficulties experienced post-diagnosis.
- Consultation and brief treatment involving processing of any experience of trauma related to the diagnosis, enhancing a sense of control and safety, psychoeducation, and encouraging family participation.

"LOW RISK" PATIENTS PROTOCOL:

- Patients will be sent follow-up information about the program in the mail, with a letter inviting the parents to call the clinic to initiate services should they

begin to develop any difficulties with adherence, for example, or significantly increased levels of distress related to the management of T1DM.

- It is important that although not all patients will present with difficulties initially, they are nevertheless informed of the services so they are aware of the resource should problems arise. The patients are also encouraged to share any difficulties to their physician in their routine appointments. This procedure is suggested per the research performed by Graff (2012). This research describes a stepped care model that allows for minimally intrusive treatment at the beginning, but which can be systematically monitored for whether an increased intensity of service is required.

B. “MODERATE RISK” PATIENTS DESCRIPTION:

- More significant family stress, adjustment issues, or socioeconomic hardship
- Anxiety, depression, and procedure-related distress that is likely to be amenable to Cognitive Behavioral Therapy (CBT) interventions

C. “HIGH RISK” PATIENTS DESCRIPTION:

- Significant levels of distress or psychopathology (e.g., depressive disorders, eating disorders, disruptive behavioral disorders, anxiety disorders, and substance use).
- Provide more intensive individual and family psychological services; work to create goals to enhance structure and safety in the environment.

MODERATE AND HIGH-RISK PATIENTS PROTOCOL:

The patients who, after the initial consult, are classified as moderate or high risk are then called by the clinic staff and are invited to schedule a full intake appointment with the psychologist as part of their overall diabetes care within the pediatric endocrinology clinic.

Once this is scheduled, the psychologist will conduct an intake and determine whether there the patient primarily presents with a co-morbid psychiatric disorder (such as Adjustment Disorder, Major Depressive Disorder, an eating disorder, etc.). It may be the case that there is not a mental health diagnosis, but instead, clear psychological or behavioral difficulties related to the primary medical diagnosis (T1DM).

Of note, this distinction is important at this time due to the billing structure (i.e. whether Current Procedural Terminology codes or Health & Behavior codes are used by the psychologist), and will ultimately assist in making the reimbursement process more streamlined.

V. DURING THE INTAKE APPOINTMENT (VISIT TWO)

Depending on the diagnostic impressions of the intake evaluator on this second visit to the clinic, the various arms of the comprehensive program are presented to the patient. These include options to schedule an additional assessment, to enroll in a group, to initiate individual or family psychotherapy, etc. Each of these activities would primarily take place during the after-school hours, and all would be located within the pediatric endocrinology clinic to enhance the sense

of receiving integrated care that does not carry any additional stigma or burden on the patient. All of the specific services are outlined in the next section.

VI. PROGRAM PARTICIPATION (VISIT THREE AND BEYOND)

Psychological services (e.g., individual or group treatment) are provided on a weekly or bi-weekly basis, depending on the need determined in the prior step(s).

The patient continues to be followed in the “Clinic Day” multidisciplinary clinic at regular intervals determined by the medical team. Details of the program are highlighted below:

- The program emphasizes cognitive-behavioral approaches, given its empirical support in the T1DM population.
- Participants are followed by the multi-disciplinary team for a comprehensive evaluation at regular intervals.
- Services are designed to manage adjustment to the disease, diabetes-related stress, family and relationship difficulties, and worries/sadness about illness-related complications.
- Assessment of behavioral and biological outcomes are integrated throughout participation in the program.
 - Adherence behaviors, diabetes-related psychological stress, mood symptoms, self-efficacy, and HbA_{1c} will be collected every 2 months
 - Diabetes-related coping skills, problem-solving skills, risky behaviors, and family/peer communication can also be collected every 2 months

- Comprehensive assessment (such as a neuropsychological evaluation or a more detailed psychodiagnostic assessment) is available on a consult basis.

Of note, the process for referring for the comprehensive program among adolescent patients who have already established their diabetes care in the clinic (and have had an established diagnosis dating prior to adolescence) is similar to what is described above. The physician, during a follow-up visit, will screen for the presence of any behavioral and/or psychological sequelae impacting the T1DM course or outcomes. Because the patient identified by the physician likely falls in the moderate or high risk category, the patient will then immediately meet with the psychologist on the same day for an intake evaluation as described above. The patient will be referred to the comprehensive program at that point and if desired, would enroll in the recommended arms of the program (i.e. additional assessment, group therapy).

SPECIFIC EVIDENCE-BASED CLINICAL INTERVENTIONS SELECTED FOR PROGRAM INCLUSION

The following interventions were found to achieve the greatest effects in the psychological and physical health of T1DM youth in well-controlled studies. Therefore, they are listed as the interventions that clinicians utilizing this program should strongly consider offering the enrolled patients. There are a total of five “intervention” arms of the treatment model.

It is important to point out that while several topics of discussion proposed for the various sessions relate to the stresses of diabetes and problem-solving around adherence issues, it is critical that providers are flexible and open to non-diabetes-related topics being raised in session. Many adolescents, regardless of their disease status, experience challenges pertaining to identity, relationships with parents, peer pressure, body image, and self-esteem. In general, adolescence can be confusing or disorienting, resulting in increased externalizing behaviors or difficulties in establishing independence. The opportunity to discuss a broad range of issues that many adolescents confront will be fruitful and beneficial. Therefore, the topics of discussion within the group and individual sessions should incorporate broader psychological and psychosocial issues experienced by adolescents. These topics could include communication with parents and peers, sexual identity and risky sexual behavior, experimentation or exposure to alcohol or drugs, academic pressure, bullying, conflicts around increased independence, and coping with negative emotions such as anger, frustration, anxiety, and depression. Addressing

these diverse issues will communicate that to the participant that all of their daily struggles are important, and will offer the opportunity to support and nurture them while promoting resilience and skills to navigate the turbulence that can be characteristic of this period. Normalization and validation of the spectrum of emotional and behavioral difficulties is essential within this population.

Psychologists will have a unique opportunity to recognize such issues as they emerge and offer early interventions that can maximize an adolescent's mental health and daily functioning. It is strongly recommended that psychologists be attuned to and respond to the broader issues raised by the participants, as remaining flexible will allow a greater cultivation of trust and significantly increase clinical effectiveness. For more details about general psychological issues and concerns in adolescence, the reader is referred to the American Psychological Association's 2002 publication entitled, "Developing Adolescents: A Reference for Professionals" (APA, 2002).

1. INDIVIDUAL COGNITIVE-BEHAVIORAL TREATMENT

Theories of health behavior change suggest that beliefs and attitudes about the self, illness, and treatment for the illness significantly influence coping and problem-solving behaviors, which, in turn, predict the course and prognosis of the disease. Adolescents who hold negative beliefs about diabetes, for example, may have decreased motivation to engage in healthy self-care behaviors, influencing glycemic control and diabetes-related complications. Theories underlying CBT

assume that thoughts and beliefs interact with affective states and have significant implications on how one copes with the daily demands of diabetes.

CBT can reduce depressive symptoms, reduce feelings of helplessness, improve diabetes self-efficacy, build various coping strategies to deal with stress and conflict, and increase self-management behaviors. For adolescents with more significant specific symptoms (of trauma or disordered eating, for instance), the individual sessions will need to be adapted beyond the core themes addressed in the following chapter.

- a. **Recommended application:** 45 minutes once per week, or as deemed appropriate, held in the clinic after school
- b. **Evidence base:** Please see the following chapter for evidence-based specific discussion points and suggested session structuring

2. GROUP COGNITIVE-BEHAVIORAL TREATMENT WITH OTHER T1DM ADOLESCENTS

These would help adolescents learn and apply stress-management techniques that can promote adherence, build coping skills, facilitate adjustment to diagnosis, reduce specific symptoms (depression, anxiety, disordered eating), and apply skills to adapt to multiple transitions' in adolescents' lives. Skills such as planning schedules around management responsibilities and planning meals and activities to maintain glycemic control can be discussed. In addition, problem-solving would be a focus, particularly those related to social situations and peer pressure (commonly

experienced by adolescents). Decision-making processes are reviewed, and problem-solving approaches are practiced. Role-play may be incorporated as well.

- a. **Recommended application:** 1.5 hours every three weeks, held in the clinic after school
- b. **Evidence base:** Please see the following chapter for evidence-based specific discussion points and suggested session structuring

3. FAMILY PSYCHOTHERAPY

This would help promote healthy, warm, collaborative family relationships and supportive family communication. Such interventions, emphasizing problem-solving and reducing conflict, would encourage flexibility in terms of the ability to shift autonomy and control from the parent to the patient as the child grows up. These interventions can be beneficial to improve management.

- a. **Recommended application:** 45 minutes once per week or as deemed appropriate, held in the clinic.
- b. **Evidence base:** Family problem-solving interventions have been shown to be effective in decreasing diabetes-related family conflict, increasing treatment adherence, as well as increasing glycemic control (Anderson, Brackett, Ho, & Laffel, 1999; Laffel et al., 2003). Family-level interventions often include behavioral contracting and behavior modification and family problem-solving.
 - i. Multisystemic therapy (MST), which intervenes at the systemic level, is home-based, and involves families, schools, and peers

(Ellis et al., 2004; Ellis et al., 2007). This can be explored as an additional component in the program, depending on the setting where this will be implemented

- ii. Behavioral family systems therapy for diabetes (BFST-D) has been tested in several randomized clinical trials by Wysocki and is a skills-based intervention that targets family problem-solving, communication, strong beliefs, and family structure, and has been shown to have an impact on important psychological variables as well as biological ones, such as glycemic control (Wysocki, 2006; Wysocki et al., 2005; Wysocki, Greco, Harris, Bubb, & White, 2001; Wysocki et al., 2007; Wysocki et al., 2008).

4. FAMILY PSYCHOEDUCATION

This would be offered to increase family knowledge of T1DM, enhance adaptive communication, and expose parents to concepts and skills taught in therapy in order to enable them to help their children apply and generalize what is learned in sessions. In addition, the major management issues in T1DM can be addressed, including the importance of nutrition, how to recognize appetite disturbance or disordered eating behavior, how to help children with using a daily food diary, how to encourage eating of snacks (and glucose monitoring) during after-school social and physical activities. A detailed review of signs and symptoms of hypoglycemia and the importance of management will be included. In addition,

affective responses to diabetes will be covered, including how depression can decrease glycemic control, and how poor control can increase depression; how adolescents may demonstrate withdrawn, avoidant, aggressive, or fearful behaviors following diagnosis; and how subjective appraisals of threat are important predictors of psychological symptoms. Normalization of the families' challenges is also important.

- a. **Recommended application:** 45 minutes once every 3 weeks or as deemed appropriate, held in the clinic. Depending on interest, these sessions can be scheduled for individual families, or they can be administered in group format.
- b. **Evidence base:** These have been studied and have been shown to be effective (Christie et al., 2009; Satin, Lagreca, Zigo, & Skyler, 1989).

5. COPING SKILLS GROUPS

This would involve problem-solving, social skills training, and conflict resolution. Such training also involves replacing ineffective coping habits with more adaptive and constructive ones. For instance, role-playing difficult social situations that would impact diabetes management can be practiced. Communication skills required to negotiate with parents about responsibilities and communicate goals with health care providers would be included.

- a. **Recommended application:** 1.5 hours every three weeks, held in the clinic after school

b. **Evidence base:** Coping skills training has been operationalized by Grey et al. (1998). Grey found that at three months follow-up, participants who received coping skills training had lower HbA_{1c} levels, higher diabetes self-efficacy, less distress about coping with diabetes, and perceived a less negative impact of T1DM on their quality of life. Coping interventions were based upon empirically-developed scenarios that were used for role-playing difficult social situations that would impact diabetes management. Communication skills required to negotiate with parents about responsibilities and communicate goals with health care providers was found to be particularly important.

Chapter VI: Sociocultural Considerations in Program

Delivery

Given that psychological assessments and treatments are designed to be delivered to an increasingly diverse pool of patients, attention to culturally-sensitive and culturally-competent care in the context of this program is critical. In the context of caring for patients with a chronic illness such as T1DM, there it is important to recognize that cultural factors are often associated with a number of significant health outcome variables, including healthcare utilization, patient-provider communication, receptiveness of the prescribed treatment, management behaviors/adherence, and of course, glycemic control.

Given the research indicating that sociodemographic risk factors such as race/ethnicity, socioeconomic status, and family structure can position T1DM youth at higher risk for poor outcomes, it is very worthwhile and important to consider these issues in program implementation. In brief, youth belonging to ethnic minorities groups, being from families of lower SES, or having only one parent living in the household are disproportionately at risk for higher HbA_{1c} values. Interestingly, many of the links between ethnic minority status, low SES, or single-parent families and poorer T1DM outcomes are thought to be mediated in part by stress and mental health issues (e.g., depression) as well as behavioral issues such as daily self-care management, which makes psychological approaches to healthcare in this population especially important.

To the extent that clinicians are aware of these health disparities in advance, triage approaches, assessment techniques, and clinical interventions can be more carefully and thoughtfully delivered to a diverse pool of patients. Knowledge of the most robust sociocultural determinants of metabolic control can help psychologists to predict challenges, barriers to care, and potential metabolic trajectories of the patients. Armed with knowledge about the ways in which cultural factors and psychological variables interact in this population of patients, issues can be more proactively and effectively dealt with early on—both on the level of the system and the individual.

Importantly, T1DM affects children and adolescents from all backgrounds, and often, cultural beliefs can affect how patients and families will seek and receive treatment from providers. As a clinician working within this program, the goal is to demonstrate that you are knowledgeable, flexible, and open to culturally-informed assessment and case conceptualization in order to achieve a more successful treatment outcome for the T1DM adolescent.

There are several points to consider when delivering care to adolescents and their families:

1. When first meeting with a patient, be open to examining the full spectrum of diversity factors. Cultural membership may include gender, race, ethnicity, sexual orientation, ability-disability status, social status (or SES), religion/spirituality, linguistic abilities, nationality, level of acculturation, immigrant/refugee status, biculturalism, geographic locale, etc. For parents

of adolescents, age and generation may also be important to consider. Ask how some of these factors would influence their participation in the program (e.g., how far is their residence from the medical center; will adolescents be able to come to appointments using transportation independently, etc.). If there are language barriers, ensure that instruments that are used are given in the appropriate language, if possible, and ensure whether an interpreter is available, if needed.

2. Seek to understand how adolescents and their families self-identify when conducting the initial intake and assessment. Some patients may identify primarily through ethnicity; others may view ethnicity as secondary to other identity components. Patients belonging to multiple cultural groups may identify more strongly with particular aspects in different contexts, such as in the medical setting. As always, it is important to recall that within-group variation may be greater than between-group variability.
3. Gather information about how adolescents and their parents understand the T1DM symptoms and/or psychological functioning. Ask for their beliefs about the cause of the illness, their understanding of the illness (“idioms of distress”) and the meanings they construct about their symptoms. Be certain to observe non-verbal behaviors that may provide more information about their feelings. Be curious about how cultural factors influence the problems or symptoms they are experiencing. Seek to understand the ways in which they are currently coping with difficulties, both psychological and medical.

4. In treatment, have a strong understanding of how interventions have previously been used with individuals and families of particular cultural backgrounds. Understand how the CBT treatment model can be tailored and adapted in a flexible manner to promote positive outcomes for patients. Consult with other professionals, and examine your rationale for using various interventions throughout the work with the adolescent.
5. Pay attention to the therapeutic relationship. Ask questions, including how your own biases and assumptions are being examined, how comfortable you are speaking about issues of diversity in treatment, and how the style of communication may be affecting treatment.

CONSIDERATIONS FOR COMMUNITY-BASED DELIVERY OF CARE

The availability of resources, whether they are financial, social, or otherwise, may determine whether an adolescent and his or her family can engage in such an intensive, comprehensive program. Children from disadvantaged socioeconomic backgrounds may lack the finances and support required to participate in a clinic-integrated program, and it may likely be that clinicians and program administrators must offer alternative ways to deliver care in many circumstances.

Offering select clinical interventions in a time-limited format within the community may ease the burden in accessing care, and may further reduce the stigma attached to receiving psychological care. While this program is designed for integration into the tertiary medical setting, the program may be adapted for inclusion into a community primary care clinic, for instance, using many of the primary guidelines offered, and the frequency of clinical interventions may be modified accordingly.

However, for families who lack health insurance or lack transportation to travel outside of their community, it may be most beneficial to build a community-based, community-driven program to address psychological needs. For instance, a program that emphasizes family/peer support as well as group CBT skills and interventions may be the most financially sustainable, and the easiest to access for some families. A particular focus on support between adolescents and their families would enable the program to rely less upon individualized psychotherapeutic

services but can still offer a structural framework to support the educational aims and promote the psychological benefits for T1DM youth and their families. In other words, while administrative and clinical support would provide the overarching framework, interventions might depend heavily on participants themselves to provide shared learning experiences for one another, promoting social support, self-efficacy, and diabetes-related knowledge and skills within communities.

For instance, such a program could be run from a community-based low-income child and family clinic. After developing a partnership with community physicians and developing plans for referrals, the program would seek referrals from physicians who could identify high-risk adolescents from medical clinics where adolescents were receiving their diabetes care. Medical doctors could then refer to the community-based program for psychosocial and psychoeducational services, held by psychologists and other mental health professionals. While such a program could offer the clinical interventions as a major aspect of care, building in social support networks and facilitating social support groups for the patients and their families within the community may be what would become most sustainable from a resources standpoint.

Program managers or trained counselors or students could lead such support groups; these would serve to increase diabetes-related knowledge, promote positive attitudes towards diabetes-related care, increase perceived levels of social support, and improve self-efficacy among adolescents and their families. Emphasizing the peer and family support elements would allow community

members to create informal networks through which families can continue to receive support and information.

Other potential adaptations for designing the program within the community could include:

1. Including incentives for families to participate: free on-site childcare, dinner, and other incentives such as grocery gift cards; to be distributed each meeting to encourage continued attendance.
2. Including sessions dedicated to didactic discussions as well as group discussions for both parents and the adolescents. Peer support forums, where the parents and the adolescents can each separately engage in dialogues such as shared experiences, may be valuable. Topics for groups of parents might include caring for the T1DM child, PTSD for caregivers, and parenting struggles. Topics for groups of adolescents might include how they have managed stress associated with diabetes or their difficulties in communication/conflict with family members. The groups will have the opportunity to voice their concerns, challenges, and successes.
3. Patients could be provided a binder of resources, worksheets, and handouts that include CBT exercises and psychoeducational material derived from CBT for T1DM adolescents. Parents may also receive a binder of parenting skills pertaining to caring for T1DM youth, adaptive family communication, and management of their own emotional responses to caregiving.

4. Homework activities could be incorporated into the program to increase between-session learning and promote application of skills outside the group context. At the end of each group therapy, the patients will choose a weekly activity to complete by the next session. A focus on providing each other emotional, informational or instrumental support can be emphasized, given the social support concentration of the community-based program. At the beginning of the next meeting, the group therapy facilitator may check who completed their assignments and if the majority completes the activity, he or she can distribute an incentive to all the participants to encourage them to engage in these activities, further fostering a sense of companionship and belonging to the group.
5. A member contact notebook for each participant can be created with the adolescent's assent and the parent's consent. This may allow for the facilitation of social support between the adolescents, contributing to the sustainability of the program after its completion.

It is important to note that adapting the medically-based program proposed in this handbook to a community-based program is not a "one-size-fits-all" approach. In order to develop a community-based program, it would be extremely important to conduct a needs assessment to determine how best to address the specialized needs of the target population, and the suggestions above should only be used to develop preliminary ideas about how to potentially adapt interventions outside of the tertiary medical setting.

Chapter VII: Cognitive-Behavioral Interventions– Suggestions for Specific Session Themes

The focus of the program with regard to the description of particular therapeutic content is cognitive-behavioral techniques for both individual and group sessions, given that CBT is the most well studied and empirically validated in the T1DM population (Hains et al., 2001; Silverman et al., 2003). CBT interventions have been shown to have high reach and feasibility.

In brief, CBT approaches blend cognitive restructuring around dysfunctional diabetes-related beliefs and appraisals with coping skills. These approaches are utilized to manage adjustment to the disease, stress levels, family and relationship difficulties, and worries about illness-related complications. This program's interventions are based, therefore, upon studies utilizing CBT to target increased treatment adherence and psychological well-being for T1DM patients.

Studies of CBT these interventions indicate that sessions typically range from 4 weeks to 48 weeks, and include both individual and group-level modalities with sessions taking place weekly for 90–120 minutes. Of note, there is no standard protocol in terms of the number or duration of sessions for this population. Therefore, recommended applications of the interventions (i.e., session duration and frequency) are described in the previous chapter.

HOW TO CONCEPTUALIZE CBT INTERVENTIONS FOR THE T1DM ADOLESCENT POPULATION

Prior studies have organized CBT treatment approaches around three phases, and this program suggests that the offered CBT sessions in your setting follow the same model in order to optimize outcomes. The program does not stipulate the time duration of each phase, as this will depend on the patient population and setting in which this program is implemented.

- I. The first phase of this specialized CBT treatment is the *conceptualization phase*.
 - Ask adolescents to describe factors that interfere with and facilitate adherence efforts
 - Have adolescents identify how they recognize effective vs. ineffective problem-solving strategies
 - Begin to collect data on adherence and relevant cognitions in the patient(s)

- II. The second phase in this model is the *skill acquisition and rehearsal phase*
 - Adolescents should be trained in cognitive restructuring
 - Practice discussing personal stressors that impact cognitions and mood
 - Develop cognitive appraisals that are more realistic and facilitative of adherence
 - Learn steps to problem-solve around common difficulties

- Given the research conducted on cognitive appraisals of chronic illnesses such as T1DM, it will be important to develop an understanding of how the T1DM adolescent appraises his or her illness.
- One target will be to modify cognitions and beliefs such that patients can perceive diabetes as a challenge rather than a threat to their lives. Challenge appraisals have been shown to be associated with an increased adherence to healthy diet (action-focused illness behaviors).

III. The third phase is the *application phase*

- Problem-solving skills are applied to new situations
- Adherence issues that are likely to arise in the future are discussed

SUGGESTED STRUCTURE FOR INDIVIDUAL AND GROUP CBT SESSIONS

With this conceptualization serving as the overarching guideline, the content of each CBT session should include the following structural elements.

A typical session (individual and group) for T1DM adolescent patients should include:

1. Agenda setting
2. Mood ratings
3. Week in review
4. Review of previous session and homework, with a focus on self-management behaviors such as blood glucose monitoring
5. Check-in on behavioral goal(s), can often be related to a management task
6. Presentation of new material/introduction of a new theme
 - a. Cognitive distortions
 - b. Emotions: sadness, fears, worries, anger
 - c. Assertive communication skills
 - d. Stress-management
 - e. Relaxation training/calming skills training
 - f. Relapse prevention
7. Discussion and exercises (e.g., role-playing, worksheets)

8. Assignment of homework

a. Problem-solving around anticipated barriers to completing homework

A special note regarding groups: In the group format, establishing goals during the first sessions(s) are critical. The main goals for the first session will be to establish a supportive community among the group members and to discuss the trajectory for the group. Therefore, activities in the first session can include introductions of each member, a review of the group rules, and discussion about group expectations. Group rules provide guidelines for creating a safe space to share, such as not interrupting the speaker, using respectful language, and allowing room for differing opinions. To promote a sharing environment and to speak to the diversity of the group, each adolescent is invited to discuss their own cultural and individual beliefs about diabetes.

SUGGESTED THEMES TO FOCUS ON DURING INDIVIDUAL AND GROUP CBT SESSIONS

Generally, themes should include the following elements, which have been suggested in the T1DM adolescent literature (e.g., Amsberg et al., 2009). Importantly, the content of individual sessions should be flexible in order to afford adolescents the opportunity to tailor discussions to their own individual demands. Generally, the following themes can guide session content in order to most appropriately address the T1DM patients' difficulties.

1. Importance of self-monitoring
2. Impact of diabetes of daily life
3. How stress affects diabetes management and health
4. Thoughts and feelings about diabetic complications in the future
5. Values in life
6. Experiencing conflict with caregivers

SPECIFIC COGNITIVE, AFFECTIVE, AND BEHAVIORAL ELEMENTS TO INCLUDE ACROSS SESSIONS

I. In the beginning of the intervention, the importance of self-monitoring should be introduced as follows:

- Adolescents should be given time to practice using a log to document and measure self-care behaviors, levels of stress, and glucose readings
- How to monitor the impact of physical and psychological stress on diabetes management should be emphasized.

II. Throughout sessions, the concept of stress should be discussed in full. Given that stress hormones impact glucose metabolism, stress management is often a priority in CBT. Stressors that many T1DM adolescents may be experiencing can include the following:

- Having to restrict the diet and deprive oneself of preferred foods
- Needing to closely monitor blood glucose several times daily and immediately deal with the oftentimes unpredictable fluctuations
- Having fear and anxiety related to inaccurately estimating necessary amounts of insulin (and the potential of ensuing hypoglycemia)
- Experiencing conflict with caregivers, both personal and professional.

The discussion about how to manage stress can include the following points:

- Elicit a discussion of current levels of stress

- Ask adolescents how their stress impacts treatment behaviors
- Normalize that in T1DM, stress triggers a more inhibited pattern of coping (avoidance and “wishful thinking”) as well as feelings of self-blame
- Describe adaptive vs. maladaptive stress management
 - Poor stress-management contributes to learned helplessness style of coping
 - Action-focused coping can improve self-efficacy
- Practice stress-reduction techniques and describe these as tools to be utilized during times of increased stress
 - Progressive muscle relaxation
 - Visualization
 - Diaphragmatic breathing
 - Mindfulness breathing (simple, short, and tailored for adolescents)

III. Socialize to the CBT model early on in treatment

- Ask participants to identify negative automatic thoughts, emotions, and somatic/behavioral reactions
 - For adolescents with depressed thoughts, the discussion can center on the types of thoughts adolescents have when they feel depressed, and the relationship between glucose readings and mood.

- Hold discussions about how to rate the validity of such negative automatic thoughts
- Identifying cognitive distortions
- Teach adolescents to “talk back to thoughts” and generate alternative thoughts.
- Develop an understanding of how an adolescent with T1DM appraises his or her illness
 - Given the research conducted on cognitive appraisals of chronic illnesses such as T1DM, it is important to modify cognitions and beliefs such that patients can perceive diabetes as a challenge rather than a threat to their lives
- Provide examples of challenge appraisals
 - These have been shown to be associated with an increased adherence to healthy diet (action-focused illness behaviors)

IV. Weave problem-solving skills into cognitive interventions throughout treatment

- Begin a discussion on how to cope with worries and anxiety
- If fears about needles are involved, speak about exposure to avoided situations and how this can maintain fears
- Describe how to plan pleasant activities and organize time

- Because diabetes is often perceived as an obstacle to enjoying pleasant activities, barriers to enjoying activities and ways to overcome those barriers should be addressed
- Planning activities while considering management issues is also beneficial, given numerous changes in adolescents' school and social routine
- Teach patients how they can evaluate progress towards stated goals
- Discuss the importance of social support networks (including family members)
 - Ask adolescents how friends and family can help them cope with difficulties as they arise
- Discuss communication skills
 - Practice speaking to others about diabetes is an important communication skill in terms of enhancing others' understanding of the disease and mitigating conflict or misunderstanding
 - Hold a discussion on how to be assertive in communication with family members and friends about diabetes so that needs are addressed
 - Ask adolescent(s) to identify their own personal communication style
 - Ask adolescent(s) whether they feel they can advocate for their needs
 - Develop strategies to respond to criticism regarding management behaviors

- Inquire about how to navigate communication with parents with regard to autonomy of self-management

V. As patients complete treatment, discuss termination issues.

- Invite to discuss experiences in individual therapy (or as members of the group)
- Help adolescents create relapse prevention plans
- Upon termination, complete a post-treatment assessment battery (see Program Evaluation chapter for further details on measures administered)

Chapter VIII: Program Evaluation

Evaluation of the iCAMP T1DM program can occur in two stages: process evaluation and outcome evaluation. Process evaluation ensures that the program is delivered as designed, and outcome evaluation measures the effectiveness of the program as a whole. Suggestions for evaluating the program are offered below.

PROCESS EVALUATION

Typically, process evaluation measures aim to assess participation in the program and patient satisfaction with the interventions. Process evaluation informs the program leaders about how program implementation is going, and can evaluate immediate (short-term) effects.

1. Participation

- a. Percentage of eligible T1DM adolescents (who receive care in the medical clinic) who enroll in the program
- b. Percentage of enrolled T1DM adolescents who participate in the program
- c. Percentage of T1DM adolescents who complete their goals (outlined at enrollment) in program
- d. Participation in various segments of the program can be assessed through session attendance logs and facilitators' activity logs.

2. Patient satisfaction

- a. Patients can be asked to complete a very brief satisfaction survey at each session. This information can be collected by the health care professional at each session; the information will be used to monitor participant progress and the program delivery.

OUTCOME EVALUATION

Outcome measurement aims to track longer-term effects of program implementation. These can include measures about the patients' knowledge, attitudes, beliefs, self-efficacy, psychological outcomes, social support, and T1DM medical outcomes. The most commonly-used measures in the T1DM adolescent literature are incorporated within the program.

While there is one biological measure (the standard HbA_{1c} blood test), many of the assessments are self-report and evaluate psychological symptoms and diabetes-specific knowledge, attitudes, and behaviors. Within the CBT model, instruments assessing frequency of behaviors and ratings of emotions and mood symptoms offer valuable information to the clinician in terms of assisting the patient in identifying connections between diabetes-related thoughts, feelings, and behaviors.

It is recommended that the interpretation of self-report measures of diabetes self-management behaviors, however, should be done with caution, as studies have shown that these scales are often not well-correlated with glycemic control due to over-reporting of these behaviors.

It is recommended that the program include the measures listed below as part of outcome evaluation, but there may be other assessments that are specifically selected for individual patients, based upon the patient's specific needs as identified at the beginning of (and throughout) the program.

TIMELINE:

It is suggested that the biological and psychological screening instruments are administered on the following schedule:

1. Pre-program enrollment (as part of the intake procedures)
2. Every 2 months throughout the patient's participation in the program (or more frequently, if indicated clinically)
3. At termination or the last scheduled visit to the clinic (which may be as late as age 18)
4. At 6 months follow-up
5. At 12 months follow-up

MEASURES:

It is recommended that the following instruments are administered in a standard fashion for all patients according to the assessment schedule above (unless otherwise specified below). Many of these instruments have been selected for inclusion in the program on the basis of the scientific validation in the adolescent population, the psychometric properties, and the utilization in healthcare settings. The length of the measure (and the time required for completion) was considered. Furthermore, instruments that included a parent report version in addition to the youth self-report version were prioritized in order to allow clinicians to gather multiple viewpoints on symptomatology.

When possible, measures that are available free-of-cost were chosen over measures that are not, in order to minimize costs. Also, in order to optimize measurement in diverse settings, instruments that have translations in other languages were selected, when available.

Importantly, research indicates that disease-specific questionnaires may be more strongly associated with health outcomes than more general measures, so diabetes-related questionnaires pre-validated in the diabetic adolescent population are included.

1. **Glycemic control/glycosolated hemoglobin:** HbA_{1c}. This is a routine measurement of glycemic control over the prior three months and is measured via a simple laboratory blood draw. One meta-analysis of behavioral interventions in this population concluded that this is most common outcome assessed; 71.4% of studies reviewed used this outcome measure (Hampson et al., 2000).
 - Of note, this measure may be taken at an increased frequency than proposed above, per medical need.

2. **Psychosocial screening of a broad range of emotional and behavioral problems in children:** Pediatric Symptom Checklist (Jellinek et al., 1988)
 - Includes subscales (attention problems, internalizing problems, externalizing problems)
 - Includes parent and youth self-report versions

- Translated into more than a dozen languages; includes a pictorial version
- 35 items (or brief versions are 17 items)

3. **Depression:** Children's Depression Inventory (Kovacs, 1992)

- Derived from the Beck Depression Inventory
- Can be used with children and adolescents ages 7-17
- Contains 27 items (youth version)
- Parent version available (17 items)
- Brief version available (CDI-Short Version), takes <5 minutes
- Written at a first-grade reading level
- Translated into multiple languages

4. **Anxiety:** Beck Anxiety Inventory (Beck & Steer, 1993)

- 21-item inventory for older children and adults; although the age range is from 17 to 80, it has been studied in children as young as age 12
- Requires only a basic reading level
- Can be administered verbally
- Spanish version exists

5. **Behavioral problems:** Youth Self Report (Achenbach, 1991)

- Ages 11-18

- 112 items to yield 8 syndrome scales (anxious/depressed; withdrawn/depressed; somatic complaints; social problems; thought problems; attention problems/ rule-breaking behavior; aggressive behavior)
- * Due to the length, it is recommended that this measure is administered should the screening tool “Pediatric Symptom Checklist” indicate further evaluation of behavioral issues

6. **Diabetes-related adjustment:** Teen Adjustment to Diabetes Scale (Wysocki, 1993)

- 21-item Likert-type scale
- Parent and adolescent forms
- Measures adolescent behavioral, affective, and attitudinal adjustment to diabetes over a 3-month period

7. **Diabetes-related quality of life:** Pediatric Quality of Life Inventory (Varni et al., 2003)

- PedsQL 3.0 Type 1 Diabetes Module is included, intended to measure specific health-related quality of life for type 1 diabetes
- Age range of 2–18 years
- Child self-report version and parent proxy-report version
- 5 scales: diabetes symptoms, treatment barriers, treatment adherence, worry, and communication

8. **Diabetes-related stress:** Diabetes Stress Questionnaire (Boardway, Delamater, Tomakowsky, & Gutai, 1993)

- 65-item self-report instrument
- Measures daily stress related to worries about diabetes, peer and family interactions, management, effects of symptoms, etc.
- Age range of 12-18 years

9. **Eating disordered behavior in diabetes:** Diabetes Eating Problem Survey–Revised (Markowitz et al., 2010)

- 16 items
- Completion time is <10 minutes
- Assesses multiple disordered eating behaviors

10. **Family conflict related to diabetes-specific tasks:** Diabetes Family Conflict Scale (Hood, Butler, Anderson, & Laffel, 2007)

- 19 items
- Assesses family conflict on specific type 1 diabetes-related tasks
- Youth and parent versions are available

11. **Behavioral ratings of diabetes adherence:** Summary of Self-Care Activities Measure–Revised (Toobert, Hampson, & Glasgow, 2000)

- 11 items; 5 additional questions about the insulin pump
- Age range is 11-17 years

- Assesses multiple domains of management
- For Spanish-speaking parents of diabetic youth, the Diabetes Self-Management Profile has been validated. The DSMP-Parent-Sp is a measure (translated into Spanish) of diabetes self-management behaviors of Hispanic youths (Valenzuela et al., 2010).

12. **Self-efficacy:** Self-Efficacy for Diabetes Management Scale (Iannotti et al., 2006)

- Assesses adolescents' perceptions of how confident they would be in 10 hypothetical situations
- Validated in adolescents

OTHER RECOMMENDED MEASURES

In addition, the following measures are also included as a suggestion for administration in the context of a family psychoeducational or group psychotherapy context, where the clinical utility may be the greatest.

1. **Diabetes-related knowledge:** Diabetes Knowledge Test (Fitzgerald et al., 1998)

- 23 items developed by the Michigan Diabetes Research Training Center
- Requires approximately 15 minutes to complete
- Written at a sixth-grade reading level
- Available as a free internet download

6. **Parental burden of caring for a child with diabetes:** Problem Areas in Diabetes Survey–Parent Version (Polonsky et al., 1995)

- Assesses perceived burden of care on the parents
- Items are answered on a 5-point Likert scale

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iCAMP T1DM

A Clinic-Integrated Program Designed to
Promote the Psychological Well-being of Type 1
Diabetic Adolescents

APPENDIX B

Program Evaluation Survey to be Used in Future Studies

Program Evaluation Survey to be Used in Future Studies

Part I: Demographics & Professional Background

For the items below, please choose the response that best describes you, or insert your response where indicated. Note: you may choose not to respond to any survey question.

1) Gender

- Male
- Female

2) Age

- Under 25
- 26–30
- 31–35
- 36–40
- 41–45
- 46–50
- 51–55
- 56–60
- 61–65
- Over 65

3) Ethnic/Racial Identification

- African American/Black
- American Indian/Alaska Native
- Asian
- Caucasian/White
- Latino(a)/Hispanic
- Native Hawaiian or Other Pacific Islander
- Biracial/Multiracial
- Other (please specify: _____)

4) Primary Professional Identification

- Clinical Psychologist: Pediatric Psychology specialty
- Clinical Psychologist: Health/Primary Care specialty
- Clinical Psychologist: General, or specialty not listed above
- Physician: Pediatrician
- Physician: Family Medicine
- Physician: Pediatric Endocrinology
- Physician: Endocrinology

- Physician: Other (specify: _____)
 - Diabetes Educator
 - Licensed Clinical Social Worker
 - Licensed Master's-level Psychotherapist (LMFT or LPCC)
 - Nurse
 - Other (please specify)
- 5) If you have a Ph.D., Psy.D., or M.D., are you currently in post-graduate training (i.e., a post-doctoral fellow in clinical psychology or a resident physician)?**
- Yes
 - No
 - Question not applicable for my degree type
- 6) How many years have you been a practicing clinician in the field identified above (including all post-graduate training years)?**
- <1
 - 1–2
 - 3–5
 - 6–10
 - 11–15
 - 16–20
 - 21–25
 - 26–30
 - 31–35
 - >36
- 7) What best describes your primary place of employment?**
- Hospital or Medical Center (not exclusively a Children's Hospital)
 - Children's Hospital or Medical Center
 - Outpatient Clinic
 - Psychiatric Hospital
 - Other
- 8) Is your institution university-affiliated?**
- Yes
 - No
- 9) What state do you currently practice in?**

10) Approximate percentage of practice that involves seeing adult patients

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

11) Approximate percentage of practice that involves seeing pediatric patients (i.e., birth through age 18)

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

12) Approximate percentage of practice that involves seeing diabetic patients (Type 1 or Type 2)

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

13) Percentage of practice serving socioeconomically-disadvantaged communities?

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

14) Percentage of practice serving non-native speakers of English?

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

15) What percentage of the time do you utilize a translator in your provision of clinical services?

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

16) Approximately what percentage of your patient panel is uninsured or relies upon public health insurance (e.g., Medicaid)?

- 0%
- <25%
- 26–50%
- 51–75%
- 76–100%

17) Does your practice involve collaboration between mental health providers and medical providers (i.e., you share in the care for a patient) on a regular basis?

- Yes
- No

18) If you answered “Yes” to Question 17, what best describes the collaboration?

- “Coordinated Care”: Minimal collaboration; separate facilities; little to periodic communication about patients
- “Co-Located Care”: Movement of patients between practices is based on referrals; most care decisions are made separately by individual providers; occasional face-to-face communication
- “Integrated Care”: Shared facilities and/or systems; frequent personal communication; integration of team member roles; providers and patients view operation as a single health system treating the whole person
- Not applicable

19) Have you ever had experience working in a setting that had *integrated care* clinics/programs (i.e., involved shared facilities and/or systems and frequent interdisciplinary communication to treat patients) for particular diseases?

- Yes
- No

20) How do you rate your personal familiarity with psychological interventions or treatment approaches targeted for patients with chronic medical diseases?

- Very Familiar
- Somewhat Familiar
- Somewhat Unfamiliar
- Unfamiliar

21) How do you rate your personal familiarity with psychological interventions or treatment approaches targeted for pediatric patients with diabetes?

- Very Familiar
- Somewhat Familiar
- Somewhat Unfamiliar
- Unfamiliar

Part II: Presentation and Evaluation of Proposed Program Contents

Please imagine a program that has the following characteristics.

Patients targeted: *Adolescent Type 1 Diabetics.*

Why? *Because of critical changes that occur during adolescence, this group is particularly at risk for poorer diabetes-related complications and health outcomes.*

- *Glycemic control typically diminishes during adolescence, which is partially attributable to hormonal changes and various behavioral problems/lifestyle issues.*
- *Non-adherence is another major risk factor.*

Treatment Team: *In the proposed program, patients would be referred to an inter-professional treatment team for evaluation and treatment of both physical and mental health needs. This team would ideally consist of:*

- Clinical Psychologists
- Physicians
- Diabetes Educators
- Social Workers
- Nurses
- Dieticians

Program Involvement: *Depending on the nature of patients' presenting issues and initial psychological assessments, the program would offer various interventions to the patients and their families.*

First step: *Triage of Patients based on level of risk for psychological or behavioral problems that are known to impact glycemic control or adherence.*

The low-risk group

- *Generally high-functioning*
- *Would benefit from attention to the most common difficulties experienced post-diagnosis.*
- *Consultation and brief treatment involving processing of any experience of trauma related to the diagnosis, enhancing a sense of control and safety, psychoeducation, and encouraging family participation.*

The moderate-risk group

- *More significant family stress, adjustment issues, or socioeconomic hardship.*
- *Cognitive Behavioral Therapy (CBT) interventions may be most effective to help address anxiety, depression, and procedure-related distress.*

The high-risk group

- *Significant levels of distress or psychopathology (e.g., depressive disorders, eating disorders, disruptive behavioral disorders, anxiety disorders, and substance use).*
- *Provide more intensive individual and family psychological services; work to create goals to enhance structure and safety in the environment.*

Second Step: *Psychological services (e.g., individual or group treatment) would be provided on a weekly or bi-weekly basis, depending on the need.*

- *The program would emphasize cognitive-behavioral approaches, given its empirical support in the T1DM population. For further details of what cognitive-behavioral treatment may be (in either individual or group format), please see below.*
- *Participants then followed by the multi-disciplinary team for a comprehensive evaluation at regular intervals.*
- *Services designed to manage adjustment to the disease, diabetes-related stress, family and relationship difficulties, and worries/sadness about illness-related complications.*
- *Assessment of behavioral and biological outcomes would be integrated throughout participation in the program.*
 - *Adherence behaviors, diabetes-related psychological stress, mood symptoms, self-efficacy, and HbA_{1c} will be collected.*
 - *Diabetes-related coping skills, problem-solving skills, risky behaviors, and family/peer communication*
 - *Comprehensive assessment (such as a neuropsychological evaluation), on a consult basis.*

Program Interventions

- ***Individual cognitive-behavioral treatment:*** *Theories of health behavior change suggest that beliefs and attitudes about the self, illness, and treatment for the illness significantly influence coping and problem-solving behaviors, which, in turn, predict the course and prognosis of the disease. Adolescents who hold negative beliefs about diabetes, for example, may have decreased motivation to engage in healthy self-care behaviors, influencing glycemic control and diabetes-related complications. Theories underlying CBT assume that thoughts and beliefs interact with affective states and have significant implications on how one copes with the daily demands of diabetes. CBT can reduce depressive symptoms, improve diabetes self-efficacy, and increase self-management behaviors.*
- ***Group cognitive-behavioral treatment with other Type 1 diabetic adolescents:*** *These would help adolescents learn and apply stress-management techniques that can promote adherence, build coping skills, facilitate adjustment to diagnosis, reduce specific*

symptoms (depression, anxiety, disordered eating), and apply skills to adapt to multiple transitions' in adolescents' lives.

- ❑ **Family psychotherapy:** *This would help promote healthy, warm, collaborative family relationships and supportive family communication. Such interventions, emphasizing problem-solving and reducing conflict, would encourage flexibility in terms of the ability to shift autonomy and control from the parent to the patient as the child grows up. These interventions can be beneficial to improve management.*
- ❑ **Family psychoeducation:** *This would be offered to increase family knowledge of T1DM, enhance adaptive communication, and expose parents to concepts and skills taught in therapy in order to enable them to help their children apply and generalize what is learned in sessions.*
- ❑ **Coping Skills groups:** *This would involve problem-solving, social skills training, and conflict resolution. Such training also involves replacing ineffective coping habits with more adaptive and constructive ones. For instance, role-playing difficult social situations that would impact diabetes management would be practiced. Communication skills required to negotiate with parents about responsibilities and communicate goals with health care providers would be included.*

Description of a “typical” CBT session in the program:

A typical session (both individual and group) will include: agenda setting, mood ratings, and week in review; review of previous session and homework, with a focus on self-management behaviors such as blood glucose monitoring; check-in on behavioral goal(s), often related to a illness management task; presentation of new material/introduction of a new theme (e.g., stimulus control techniques, assertive communication skills, stress-management, and relaxation training); discussion and exercises (e.g., role-playing, worksheets); and assignment of homework (and problem-solving around anticipated barriers to completing homework).

Generally, themes will include the importance of self-monitoring, impact of diabetes of daily life, how stress affects diabetes management and health, thoughts and feelings about diabetic complications in the future, and experiencing conflict with caregivers. The problem-solving skills that will be taught and practiced include how to cope with worries and anxiety (through exposure to avoided situations, for example), how to be assertive in communication with family members and friends about diabetes, how to plan pleasant activities and organize time, and how to evaluate progress towards stated goals.

Importantly, the content of this program will be flexible and will afford adolescents the opportunity to tailor discussions to their own individual demands.

You are now asked to provide your opinions about the proposed program.

Please rate the extent to which you agree with the following statements (according to the scale).

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

- 1) The program's objectives are relevant to the needs of diabetic adolescents.
- 2) The interventions selected (e.g., CBT psychotherapy, family psychoeducational groups, on-going symptom assessment) are consistent with the program's objectives.
- 3) Compared to not participating in a program like this one, diabetic pediatric patients would benefit from participating in terms of their psychological and psychosocial well-being (i.e., may reduce psychological/behavioral risk factors and/or may promote psychological health).
- 4) Compared to not participating in a program like this one, diabetic pediatric patients would benefit from participating in terms of their physical health (i.e., interventions may lead to improved glycemic control)
- 5) Diabetic adolescents would be willing to participate in a program like this one.
- 6) Parents of diabetic adolescents would be interested in a program that offered the services outlined for their child.
- 7) A program that delivers these types of services is needed for diabetic children and/or adolescents.
- 8) Based on your professional experience, indicate the top 3 programmatic elements you consider the MOST valuable in the comprehensive care of type 1 diabetic adolescents.
 - Coping skills training groups (including problem-solving and social skills training involving role-playing social situations that could impact management)
 - Individual psychotherapy using cognitive-behavioral approaches
 - Group psychotherapy using cognitive-behavioral approaches
 - Stress management group
 - Family-related interventions (increase adaptive communication skills, problem-solving)
 - Family psychoeducation group
 - Comprehensive assessments for identified patients (psychodiagnostic, neuropsychological evaluation)
 - Other (please specify): _____

9) Based on your professional experience, please indicate the top 3 programmatic elements you consider the LEAST valuable in the comprehensive care of type 1 diabetic adolescents.

- Coping skills training groups (including problem-solving and social skills training involving role-playing social situations that could impact management)
- Individual psychotherapy using cognitive-behavioral approaches
- Group psychotherapy using cognitive-behavioral approaches
- Stress management groups
- Family-related interventions (communication skills, problem-solving)
- Family psychoeducation group
- Comprehensive assessments for identified patients (psychodiagnostic, neuropsychological evaluation)
- Other (please specify): _____

10) Based on your professional experience, indicate the top 3 patient outcomes you consider to be MOST LIKELY to result from patients' participation in this program.

- Improvement of health-related quality of life
- Reduction of psychiatric symptoms (depression, anxiety)
- Reduction of stress and increased application of stress-management techniques
- Improved resiliency and coping
- Improved family communication and problem-solving around common adolescent-parent difficulties related to illness management
- Reduce healthcare utilization for urgent care visits and hospitalizations
- Improve adherence (diet, glucose monitoring, insulin injection, self-care behaviors)
- Improved glycemic control
- Improved adjustment difficulties related to diagnosis
- Improved patient self-efficacy
- Other (please specify)

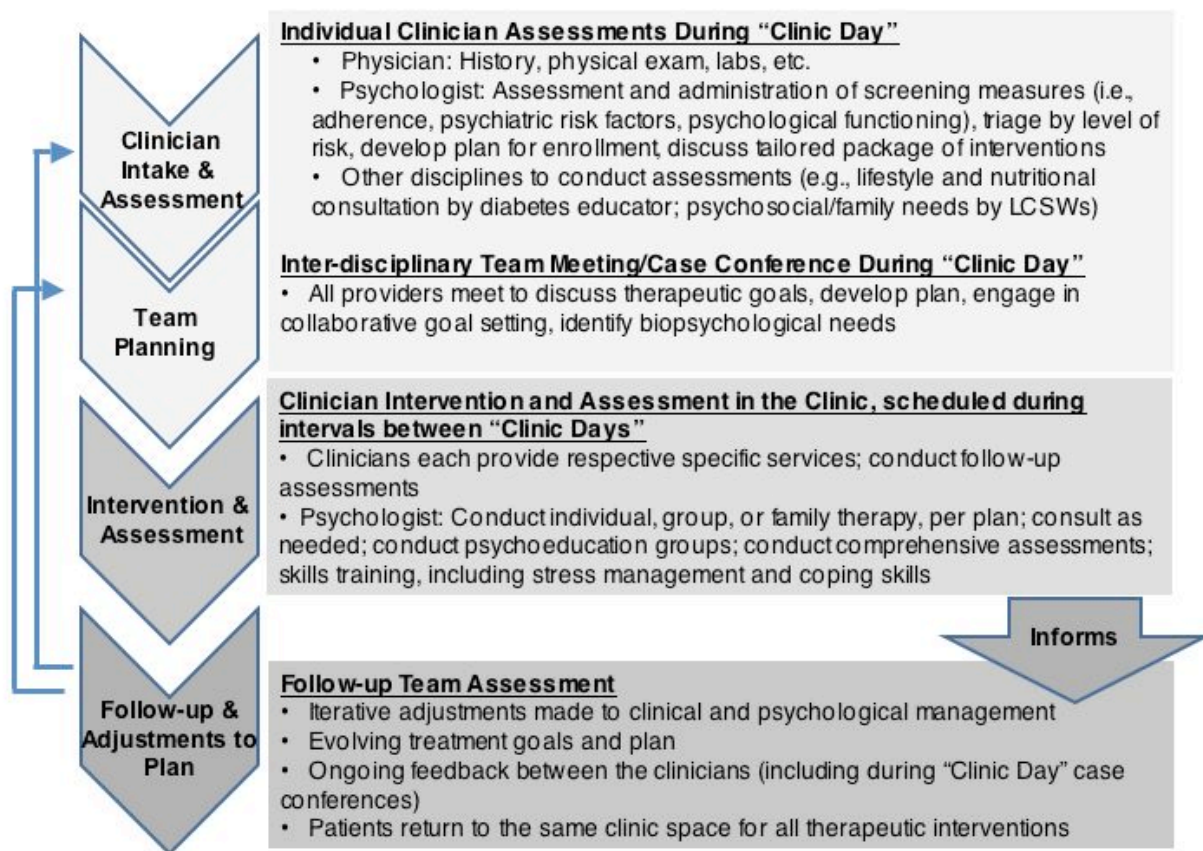
11) Please comment on your beliefs about the limitations of or problems with the proposed program (e.g., what might you revise, add, or omit?)

Part III: Presentation and Evaluation of Proposed Program Structure

Please imagine that the program is designed for implementation in an “integrated health care” setting.

Integrated health care has been defined by the American Psychological Association (2007) as follows: “Integrated health care is often referred to as interdisciplinary health care or interprofessional health care. This approach is characterized by a high degree of collaboration across the various health professionals serving patients in assessment, treatment planning, treatment implementation, and outcome evaluation...” (p. 15) and “What characterizes this work as integrated in nature is the emphasis on interdisciplinary communication to facilitate ongoing, iterative adjustments of the treatment plan, the consideration of psychosocial as well as biomedical issues affecting the patient, and clear communication about the unique roles played by each collaborator in order to facilitate team functioning and patient-centered care” (p. 39).

Please imagine that this program is structured in the following ways.



Please rate the extent to which you agree with the following statements (according to the scale).

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

- 1) Diabetic patients and their families would find this format of delivery of services more appealing and valuable *than existing delivery formats*.
- 2) My fellow clinicians treating diabetic patients would find this format of delivery of services more appealing and valuable than existing delivery formats.
- 3) Delivering comprehensive services in this format would help enable the identification of and the treatment of high-risk patients *more than existing practices*.
- 4) Delivering comprehensive services in this format would help provide culturally-responsive care for a diverse population of patients *more than existing practices*.
- 5) Delivering comprehensive services in this format can help to coordinate psychological care *more than existing practices*.
- 6) An integrated-care format is more likely to result in improved psychological and physical health outcomes for diabetic patients *than care that is not delivered in this format*.
- 7) Based on your professional experience, please state what you view as the primary barriers to adoption of a program delivered in this format.

Part IV: Integrated Care Knowledge, Attitudes, and Beliefs

The items below ask for your professional opinions about integrated health care, in general. Please choose the response that best reflects your opinion.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

- 1) I am aware of the Patient Protection and Affordable Care Act legislation and how this might impact inter-disciplinary clinical practice.
- 2) I am open to practicing within an inter-disciplinary care environment that involves collaboration on creating treatment plans for individual patients.
- 3) I believe integrated care is an impractical and unrealistic approach to health care serving patients with chronic diseases.
- 4) Integrating mental health with general healthcare services produces the best outcomes and is the most effective approach to caring for patients with multiple, complex healthcare needs.
- 5) Collaboration in this model would enable the team to be more sensitive to the full array of patient diversity issues.
- 6) I believe this approach is unviable from an administrative perspective (i.e., logistically, it would be infeasible to staff clinics, share office and clinic space).
- 7) I believe this approach is viable from a professional communication perspective (i.e., to work alongside, consistently communicate, and plan care with other providers).
- 8) I believe this approach is viable from an economic perspective (i.e., financially, it would be feasible to implement and run).
- 9) I believe that this approach would pose billing/reimbursement issues for clinicians.
- 10) The institution in which I am currently employed would be supportive of such an approach.
- 11) In the future, integrated health care approaches will be more limited than they are now.
- 12) Please describe what you believe the impact of integrated health care on the future of psychological services (or medical services) will be.
- 13) Please provide any other comments about your opinions of integrated psychological/behavioral care and how this might impact practice. Please include your concerns about this approach (potential barriers to implementation).