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Youth With Type 1 Diabetes Mellitus: An Examination Of Adolescents’ Illness Perceptions And Associated Impact On Health-Related Quality Of Life

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YOUTH WITH TYPE 1 DIABETES MELLITUS: AN EXAMINATION OF ADOLESCENTS’ ILLNESS PERCEPTIONS AND ASSOCIATED IMPACT ON HEALTH-RELATED QUALITY OF LIFE

A Dissertation
presented in partial fulfillment of requirements
for the degree of Doctor of Philosophy
in the Department of Pharmacy Administration
The University of Mississippi

by

ZAINAB SHAHPURWALA

December 2015
ABSTRACT

Objectives:

To examine the impact of various psychosocial factors (perceived stress, diabetes-specific parental involvement, self-efficacy for diabetes management, and perceived peer support) on adolescents’ self-reported health-related quality of life (HRQoL) and assess the association between these factors and their self-reported HRQoL.

To determine if differences in perceptions exist between diabetes camp and non-camp adolescent attendees on the various aforementioned psychosocial factors and their impact on their HRQoL.

Methods:

The study employed a cross-sectional, non-experimental, quantitative design to address the aforementioned objectives. Adolescents were recruited from multiple sites including diabetes summer camps and university-based and community-based private clinics. Self-administered paper-based surveys were administered to adolescents with T1DM by a member of the research team. Structural equation modeling was utilized to test the proposed study model and examine the relationships hypothesized therein.
Results:

The final model fit the data well and explained 49.1%, 40.4%, 59.1%, and 26.9% of the variance in physical, emotional, social and school functioning (i.e., domains of HRQoL) among adolescents with T1DM, respectively. Higher levels of perceived diabetes severity were found to be associated with higher levels of perceived stress and poorer HRQoL. Higher levels of self-efficacy for diabetes management were found to be associated with lower levels of perceived stress and better HRQoL. Lastly, higher levels of perceived stress were also associated with poorer HRQoL. No significant differences in the various illness perceptions that were assessed in this study or their impact on perceived stress and quality of life were found among adolescents with T1DM who frequent diabetes camps versus those who don’t (diabetes clinic population).

Conclusion:

This research addresses an important gap in the literature by clarifying the impact of various social-behavioral factors, which are amenable to intervention, on the HRQoL of adolescents with T1DM. The findings from this study will enable the delivery of more directed patient-centered care by providing insight to help improve the HRQoL of young people living with T1DM. It opens a window of observation in an area that has not been widely researched before -- social behavioral influences on comprehensive care for youth with T1DM, an underrepresented population.
DEDICATION

I dedicate this dissertation to Ma, Papu and Nana, without whose unending love and support this would have been impossible.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>TITLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Dedication</td>
<td>iv</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>v</td>
</tr>
<tr>
<td>List of Tables</td>
<td>viii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>ix</td>
</tr>
<tr>
<td>Chapter I: Background and Significance</td>
<td>1</td>
</tr>
<tr>
<td>Chapter II: Literature Review</td>
<td>10</td>
</tr>
<tr>
<td>Chapter III: Research Design and Methods</td>
<td>32</td>
</tr>
<tr>
<td>Chapter IV: Results</td>
<td>54</td>
</tr>
<tr>
<td>Chapter V: Discussion and Implications</td>
<td>71</td>
</tr>
<tr>
<td>Bibliography</td>
<td>85</td>
</tr>
<tr>
<td>List of Appendices</td>
<td>108</td>
</tr>
<tr>
<td>Appendix A: Survey Instrument</td>
<td>109</td>
</tr>
<tr>
<td>Appendix B: Materials for Diabetes Clinics</td>
<td>125</td>
</tr>
<tr>
<td>Appendix C: Materials for Diabetes Camps</td>
<td>132</td>
</tr>
<tr>
<td>Vita</td>
<td>144</td>
</tr>
</tbody>
</table>
## LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Study Variables – Skew and Kurtosis</td>
<td>56</td>
</tr>
<tr>
<td>2: Study Variables – Tests of Normality</td>
<td>57</td>
</tr>
<tr>
<td>3: Study Characteristics</td>
<td>58</td>
</tr>
<tr>
<td>4: Study Variables – Descriptive Statistics</td>
<td>59</td>
</tr>
<tr>
<td>5: Study Variables – Correlations</td>
<td>60</td>
</tr>
<tr>
<td>6: Measurement Model – Standardized Loading Estimates</td>
<td>62</td>
</tr>
<tr>
<td>7: Measurement Model – Reliability Estimates</td>
<td>62</td>
</tr>
<tr>
<td>8: Structural Model – Standardized Total, Direct and Indirect Effects</td>
<td>65</td>
</tr>
<tr>
<td>9: Structural Model – Mediation Analysis</td>
<td>66</td>
</tr>
<tr>
<td>10: Mann-Whitney U Test</td>
<td>68</td>
</tr>
<tr>
<td>11: Test of Homogeneity of Variances</td>
<td>68</td>
</tr>
<tr>
<td>12: Multi-group Analysis</td>
<td>70</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Wallander and Varni’s Conceptual Model of Child Adjustment to Pediatric Chronic Physical Disorders (Risk and Resistance Model)</td>
<td>14</td>
</tr>
<tr>
<td>2: Proposed Study Model</td>
<td>16</td>
</tr>
<tr>
<td>3: Measurement and Structural Model</td>
<td>52</td>
</tr>
<tr>
<td>4: Final Structural Model</td>
<td>63</td>
</tr>
</tbody>
</table>
CHAPTER I

BACKGROUND AND SIGNIFICANCE

Type 1 Diabetes Mellitus (T1DM) in Adolescents

Type 1 Diabetes Mellitus (T1DM), a metabolic disorder, is one of the most common chronic diseases in childhood (Kelo, Martikainen, & Eriksson, 2011). T1DM affects approximately 1 in every 400 to 500 youth ages 10 to 19 years in the United States (U. S.) and data suggest that these rates are on the rise (Liese et al., 2006). Adolescence is a critical period of development and is a transitional stage given that it is accompanied by changes in interpersonal roles, responsibilities, and identity development (Ingerski, Anderson, Dolan, & Hood, 2010a). Thus, it is reasonable to expect that these years are more complex for adolescents diagnosed with T1DM. In addition to the usual stressors encountered during this developmental period in their life, adolescents have to face additional emotional and physical stressors associated with having and managing their diabetes (Lawrence et al., 2012). Further, adolescents must cope with intensive medical regimens that consist of multiple daily insulin injections or use of an insulin pump, regular clinic appointments, frequent monitoring of blood glucose levels, regulation of carbohydrate intake, regular exercise, and correction of abnormally high (hyperglycemia) or low (hypoglycemia) blood glucose (Silverstein et al., 2005). Youth and their families need to expend
considerable amount of time, energy, and effort on a daily basis in order to follow the
aforementioned treatment recommendations (Whittemore, Jaser, Guo, & Grey, 2010).

Wallander and Varni’s Risk and Resistance Model

Wallander and Varni developed the Risk and Resistance model in order to encompass the
experiences of families with chronically ill children. The model has also been used to understand
how children adapt to chronic physical disorders (Wallander & Varni, 1998). It is based on
previous theories of adjustment to chronic disease, family coping, and cognitive appraisal and is
intended to be generic so as to be potentially applicable to a variety of pediatric chronic
disorders. According to this model, chronic physical disorders like T1DM are characterized as an
ongoing strain and risk and resistance factors impede and facilitate adjustment to chronic illness,
respectively (See Figure 1) (Wallander & Varni, 1992). Disease and disability parameters,
functional independence and psychosocial stressors are the three categories of risk factors
included in this model. Intrapersonal factors, socioecological factors, and stress processing
factors are the three categories of resistance factors that are included in the model (Wallander &
Varni, 1992, 1998). Wallander and Varni’s Risk and Resistance Model was utilized as a guiding
framework for this study (Wallander & Varni, 1998).

Adolescents’ Illness Perceptions

Adjustment (or adaptation) to one’s illness during childhood sets the stage for later
adjustment (or adaptation) in adulthood (Heimlich, Westbrook, Austin, Cramer, & Devinsky,
As discussed earlier, adolescence is a particularly significant developmental period for those with a chronic health condition (e.g., T1DM) (Ingerski et al., 2010a; Lawrence et al., 2012). A child’s feelings about and how he/she copes with his/her illness may be intimately related to the child’s feelings about himself/herself (Austin & Huberty, 1993). Therefore, it is conceivable that adolescents’ perceptions related to their illness may influence their adaptation to their condition as well as influence their ability to meet some of the challenges of adolescence.

Adolescents’ Illness Perceptions and HRQoL

**Perceived stress.** Stress plays an important role among adolescents with T1DM, affecting metabolic control either by directly impacting physiological functioning or indirectly by detracting from diabetes self-management (Goldston, Kovacs, Obrosky & Iyengar, 1995). Studies have shown that children with high life stress tend to have worse glycemic control (Hains et al., 2007; Hanson & Pichert, 1986). Further, diabetes-specific stress has also been linked to poor glycemic control (La Greca & Bearman, 2002).

**Perceived diabetes-specific parental involvement.** Adolescents with T1DM as a group display the worst glycemic control compared with other age groups (de Wit et al., 2008). During adolescence, less than optimal metabolic control and adherence to treatment guidelines, as well as severe noncompliance is commonplace (La Greca et al., 1995). Sustained levels of parental involvement during adolescence are necessary for optimal diabetes management across this time (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). Research has found that when parents are involved with their adolescent through a high quality relationship, actively monitoring their adolescent’s behavior and behavioral management in diabetes tasks, both adherence and metabolic control are improved (Berg et al., 2011). Further, a study by Weissberg-Benchell et al.
(2009) found that children whose parents remained involved in their diabetes care reported higher levels of HRQoL. Research also indicates that shared responsibility for diabetes management tasks is associated with better psychological adjustment and self-management in adolescents (Anderson et al., 2002; Berg et al., 2008).

**Perceived diabetes-specific peer support.** Adolescents spend most of their time in the confines of school or in a leisure setting with their friends (Kuttler, La Greca & Prinstein, 1999). Thus, it is only natural that peers will have an influence on one another’s development. As they progress through adolescence these individuals will actively seek independence from their parents and place a higher level of importance on their relationships with their peers (Lowes, Eaton, Bill, & Ford, 2007). Since T1DM does not exist in a social vacuum, it is important to recognize the influence peers might have on diabetes management and adaptation to the condition among adolescents with T1DM. Friends may provide emotional support, companionship as well as practical support for management of T1DM among afflicted adolescents (La Greca et al., 1995). However, studies have shown that friends can have the opposite effect as well. For example, Thomas, Peterson, & Goldstein (1997) reported that adolescents tend to choose behaviors that are less regimen adherent and instead opt for behaviors that are consistent with their peers’ desires.

**Self-efficacy for diabetes management.** Bandura (1986) defines self-efficacy as the belief that one can carry out specific behaviors under specified circumstances. In children and adolescents with T1DM, the perception of self-efficacy has been found to be associated with improved family functioning, self-management, metabolic control as well as psychosocial adjustment (Griva, Myers, & Newman, 2000; Ott, Greening, Palardy, Holderby, & DeBell, 2000; Iannotti et al., 2006). Self-efficacy has also been associated with enhanced quality of life (Grey,
Research Significance

T1DM is a chronic condition; thus, the impact of the condition will unfold over time and persist for life. Considering the significant challenges to youth and their families, there is a great need to develop innovative interventions that are developmentally appropriate and address the complex physiologic, psychosocial, and family processes that influence adaptation to T1DM (Whittemore et al., 2010). Identifying factors that might promote good diabetes management and disease adaptation will provide a foundation for the development of psychosocial care interventions to enhance positive attitudes and, ultimately, psychosocial adjustment in children with T1DM (LeBovidge, Lavigne, & Miller, 2005).

Self-efficacy for diabetes management, diabetes-specific parental involvement and peer support are potential targets for interventions to address poor adaptation in children with T1DM. Although some research has been conducted on the impact of these aforementioned factors on direct outcome markers such as blood glucose levels, there is incomplete understanding of their impact on relevant outcome measures such as HRQoL.

Psychosocial interventions that can improve adaptation among adolescents might include encouraging children to talk with their parents about their condition. For example, communication about strategies for dealing with side-effects of diabetes treatment (e.g., hypoglycemia) or other diabetes-related symptoms and talking about the child’s future might be topics for communication in interventions (Austin, Dunn, Perkins, & Shen, 2006). Examples of
other psychosocial interventions that can promote adaptation to T1DM during childhood and adolescence include, supporting collaborative parent-child management of T1DM, providing opportunities for the child to gain self-efficacy in self-management of T1DM, and promoting positive family functioning (Whittemore et al., 2010). An increasing body of research supports the importance of family teamwork and shared regimen responsibility for metabolic and psychosocial outcomes (Anderson et al., 2002; Laffel et al., 2003). Further, research indicates that the manner in which parents demonstrate involvement in diabetes management is more important (with respect to the child’s HRQoL) than the specific amount of responsibility taken by the parent. Taken together with previous findings, these results underscore the importance of parents working with their child in caring for their daily diabetes regimen demands, providing both shared responsibility as well as a collaborative style of involvement to enhance both metabolic and psychosocial outcomes (Weissberg-Benchell et al., 2009).

In terms of peer support, psychosocial interventions that involve training friends to be more involved in adolescents’ management of their diabetes may be undertaken (Wysocki & Greco, 2006). However, as a first step adolescents also need to be trained to disclose their condition to their friends in order to successfully engage in diabetes care. Interventions that improve friends’ knowledge about diabetes may also be beneficial in that they may help alter friends’ perceptions of the disease (Greco, Pendley, McDonell & Reeves, 2001). Friends provide social support unique from parents’ contribution and provide an important source of emotional support which in turn may help improve adolescents’ self-management of diabetes.

Adolescents with chronic illnesses such as T1DM have both physical and emotional needs that surpass those of adolescents without chronic illnesses. Disease-specific camps (e.g., T1DM summer camp) can provide an environment where adolescents with chronic diseases can
learn positive coping skills and strategies. They can take the skills and confidence gained at the camp setting and apply the same to their normal environment at home (Ramsing & Sibthorp, 2008). Experiences gained during such camps may help adolescents gain a deeper understanding of their condition and may also help them recognize their true potential in spite of their condition. Additionally, being in the safe environment of a camp in the company of others like themselves, adolescents may realize that they are not alone in their fight against their condition and that they can accomplish tasks that they previously thought impossible (Timmons, 2009). Thus, such camps are an effective means to train youths and help them adopt a healthy attitude toward their condition.

Currently, limited understanding exists regarding the differences in perceptions of adolescents with T1DM who frequent diabetes camps versus those who don’t on various factors such as perceived stress, self-efficacy for diabetes management, diabetes-specific parental involvement and peer support. Based on our aforementioned discussion, we expect that attending a diabetes summer camp will positively influence camp attendees and thus, their adaptation to their condition.

In summary, the objectives of this study are to: (1) examine the impact of various factors (perceived stress, diabetes-specific parental involvement, self-efficacy for diabetes management, and perceived peer support) on adolescents’ self-reported Health-related Quality of Life (HRQoL); (2) assess the association between these factors and their self-reported HRQoL; and (3) determine if differences in perceptions exist between diabetes camp and non-camp adolescent attendees on their perceived level of stress, their perceived parental involvement and peer support, their ability to manage their condition and their HRQoL.
A comprehensive review of the literature was conducted in order to gain insight into the existing information regarding various factors (perceived stress, diabetes-specific parental involvement, self-efficacy for diabetes management, and perceived peer support) associated with having T1DM. Next, a cross-sectional, non-experimental study was conducted using a paper-based survey in order to assess the influence of the stated factors on adolescents’ self-reported HRQoL. A structural equation modeling (SEM) approach was employed in order to address the research objectives. The model proposed in this study was tested with the following hypotheses:

1. Adolescents’ perceived disease (i.e., T1DM) severity will be negatively related to their self-reported HRQoL.
2. Adolescents’ perceived stress regarding having T1DM will be negatively related to their self-reported HRQoL.
3. Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be positively related to adolescents’ self-reported HRQoL.
4. Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be negatively related to their perceptions of stress.
5. Adolescents’ perceived diabetes-specific peer support will be positively related to their self-reported HRQoL.
6. Adolescents’ perceived diabetes-specific peer support will be negatively related to their perceptions of stress.

1 All the hypotheses are stated in their alternative forms.
H7: Adolescents’ self-efficacy for diabetes management will be positively related to their self-reported HRQoL.
CHAPTER II

LITERATURE REVIEW

Type 1 Diabetes Mellitus (T1DM) is a chronic childhood condition that is characterized by a non-existent supply of insulin, such that the body cannot control blood glucose levels (Amer, 2008). Individuals afflicted with this condition are advised to regulate their own blood glucose levels through frequent monitoring of the same, controlling carbohydrate intake, carrying out daily insulin treatment and adjusting insulin dosages to match one’s diet and activity patterns (Kelo, Martikainen & Eriksson, 2011). If individuals do not engage in adequate self-care behaviors, it can result in complications, which if left untreated may lead to coma or even death (Diabetes Control and Complications Trial [DCCT] Research Group, 1994). For children with T1DM, the transition into adolescence is frequently marked by declines in adherence, metabolic control, psychosocial well-being (Wiebe et al., 2005), self-care behaviors (or diabetes self-management) as well as overall control of diabetes (Skinner & Hampson, 1998). These findings are of great concern because research has demonstrated that adolescents who fail to engage in adequate diabetes self-care behaviors have reduced life expectancy and are at risk of developing diabetes-related complications (e.g., hypoglycemia), anxiety, and depression (DCCT Research Group, 1994). Research that attempts to predict and improve diabetes management and adaptation in adolescents is therefore very important. Metabolic control is considered to be the primary marker of physiological adaptation to T1DM because research has demonstrated that
it is clearly responsible for delaying and/or preventing the development of long-term diabetes complications (DCCT Research Group, 1994).

Health-Related Quality of life (HRQoL), a qualitatively different but important outcome along with metabolic control, has been increasingly recognized as a key psychosocial outcome in youth with T1DM (Whittemore et al., 2010). The reason for this increased focus on HRQoL stems partially from the Diabetes Control and Complications Trial (DCCT Research Group, 1996) as well as from growth in awareness of HRQoL as a central outcome in healthcare and health policy (Delamater, 2000). HRQoL is a measure of the extent to which a medical condition influences the physical and psychosocial well-being of an individual (Cameron, 2003). It is considered an important indicator of quality of care in pediatric diabetes because traditional indicators, such as metabolic control and frequency of acute complications fail to accurately reflect the burdensome and challenging demands of managing this condition (Graue, Wentzel-Larsen, Hanestad, Båtsvik, & Søvik, 2003). Thus, HRQoL has emerged as an informative and widely accepted health outcome measure to assess the multidimensional impact of a chronic illness on children’s overall well-being (Ingerski et al., 2010b).

In studies of children with diabetes, measurement of the construct (i.e., HRQoL) varies in dimensions, but usually includes aspects of physical, emotional, and social well-being (Rubin & Peyrot, 1999). Both generic and disease-specific instruments have been utilized to assess HRQoL in children with T1DM. Generic instruments (e.g., Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales) as the name suggests are more general in nature and allow for comparisons between children with diabetes and healthy children or children with other conditions (Patrick & Deyo, 1989). On the other hand, disease-specific instruments (e.g., Diabetes Quality of Life – Youth (DQOLY) Scale), “allow for the assessment of dimensions that
are uniquely relevant to the lives of children with diabetes and therefore may be more sensitive to change or between-group differences” (Nansel, Weisberg-Benchell, Wysocki, Laffel, & Anderson, 2008, p. 1316).

**Health-Related Quality of Life (HRQoL) among Children and Adolescents with T1DM**

Research has identified a large number of demographic, clinical, and psychosocial correlates of HRQoL among youth with T1DM using either generic or disease-specific instruments. The association between HRQoL and glycemic control has been assessed in a large number of studies wherein the construct has been linked to better glycemic control (i.e., lower glycosylated hemoglobin (HbA1c) values) (Hesketh, Wake, & Cameron, 2004; Hoey et al., 2001; Hassan, Loar, Anderson & Heptulla, 2006; Lawrence et al., 2012; Wagner, Müller-Godeffroy, von Sengbusch, Häger, & Thyen, 2005). Given that insulin pump therapy is increasingly used as part of routine diabetes care, researchers have assessed the association between HRQoL and regimen prescription. Owing to the superior health benefits and flexibility afforded by insulin pump therapy, it was expected that pump therapy would be related to better HRQoL as compared to multiple daily injection regimens. However, this association was not seen consistently across studies (McMohan et al., 2005; Valenzuela et al., 2006). The SEARCH for Diabetes in Youth Study Group found significant independent associations between HRQoL and a number of different demographic (e.g., age, gender, and regimen type) and clinical characteristics (e.g., HbA1c values, and depressive symptoms) in a large, diverse cohort of youth with T1DM (Lawrence et al., 2012). Across different studies, greater Body Mass Index (BMI) has also been found to be associated with poorer HRQoL (Hoey et al., 2001; Schwimmer,
Burwinkle, & Varni, 2003; Williams, Wake, Hesketh, Maher, & Waters, 2005). Further, studies have also demonstrated relationships between HRQoL and various dimensions of family functioning in children with T1DM (Laffel et al., 2003; Weissberg-Benchell et al., 2009; Whittemore, Urban, Tamborlane, & Grey, 2003; Wysocki & Gavin, 2006).

**Wallander and Varni’s Risk and Resistance Model**

Children that are chronically ill must face as well as cope with various situations that are stressful on a daily basis. These situations may be episodic acute exacerbations of their chronic disease or may be potential long-term functional limitations that may accompany their disease (Varni, Wilcox, & Hanson, 1988). The risk and resistance model is based on previous theories of adjustment to chronic disease, family coping, and cognitive appraisal. It was developed in order to encompass the experiences of families with chronically ill children and has also been used to understand how children adapt to chronic physical disorders (Wallander & Varni, 1998). The model is intended to be generic so as to be potentially applicable to a variety of pediatric chronic disorders. According to this model, chronic physical disorders like T1DM are characterized as an ongoing strain and risk and resistance factors impede and facilitate adjustment to chronic illness, respectively (See Figure 1) (Wallander & Varni, 1992).

Disease and disability parameters, functional independence and psychosocial stressors are the three categories of risk factors included in this model. These are primarily responsible for causing adjustment problems in children with chronic physical disorders. It is conceivable that children with similar risk factors may display wide differences in adjustment, making this relationship a complex one. Therefore, resistance factors are thought to influence this risk-
adjustment relationship. Three categories of resistance factors that are included in the model are intrapersonal factors, socioecological factors, and stress processing factors (Wallander & Varni, 1992, 1998).

Risk Factors. A number of disease and disability parameters may put children at risk for adjustment problems. Merely having a chronic physical disorder like T1DM can put children at risk for adjustment. Adjustment is also thought to co-vary with the severity of the child’s
condition as well as the visibility of the condition (Wallander et al., 1988). A condition like T1DM which is highly visible, e.g., children have to regularly check and adjust their blood glucose levels, may cause social stressors which in turn may affect adjustment.

A closely associated, yet conceptually different risk factor is the functional independence displayed by the child in relation to age expectations. A child’s ability to function independently will be impacted to varying degrees by his/her chronic physical condition. Functional activities that may be impacted include activities of daily living, communication and the child’s involvement with significant others and the community at large (Pless & Roghmann, 1971).

Psychosocial stressors are the third category of risk factors that may influence a child’s adjustment to his/her chronic physical condition. These children have to deal with disease and disability related stressors that their healthy peers do not usually experience on a daily basis. Additionally, these children may find it harder to confront daily stressors that are experienced by most other children their age as a result of their pre-existing disease and disability related stressors (Wallander & Varni, 1998).

**Resistance Factors.** The impact of various risk factors on adjustment may be buffered by the presence of various resistance factors, including intrapersonal, socioecological, and stress processing (Wallander & Varni, 1992). Research has demonstrated that a child’s personal characteristics may influence the risk-adjustment relationship. However, it may be challenging to define a priori which characteristics may play a role in influencing this relationship. Some characteristics that have been previously studied include temperament, social problem-solving ability, etc. Next, among the various relevant characteristics of the social environment in which the child lives, this model emphasizes relationship within the family, adjustment of family
members, and social support as being central to the adjustment of a child with a chronic physical condition. Lastly, given the significant role of psychosocial stressors in this framework and based on the theory of stress and coping put forth by Lazarus and Folkman (1987), this risk and resistance model emphasizes the role of cognitive appraisal of and coping with stress in order to explain difference in adjustment among children with chronic physical conditions (Wallander & Varni, 1998).

Figure 2. Proposed Study Model
Wallander and Varni’s Risk and Resistance Model was utilized as a guiding framework for this study (Wallander & Varni, 1998). Diabetes care poses a constant challenge on the well-being of the adolescent while coping with the demands of this chronic metabolic disease. HRQoL serves as an important comprehensive indicator of the health condition of a particular person and thus, the study model included HRQoL as a measure of psychosocial adjustment/adaptation in children with T1DM. It excluded physiological adjustment/adaptation (i.e., metabolic control) because it is difficult to measure the same in survey-based research and it has been previously explored in the extant literature. Consistent with the Risk and Resistance Model, disease severity, psychosocial stress (e.g., perceived stress), personal factors (e.g., self-efficacy for diabetes management) and social ecological factors (e.g., parental involvement and peer support) directly influenced a child’s psychosocial adaptation to his/her disease (i.e., T1DM). The study model also assessed if the aforementioned social ecological factors indirectly influenced psychosocial adaptation through psychosocial stress (See Figure 2).

Adolescents’ Illness Perceptions

There is a growing trend of understanding perceptions children have of their illness from their own point of view. Research has found that children are able to competently communicate their experiences of ill health and healthcare in general (Sartain, Clarke, & Heyman, 2000). In addition to the psychosocial fears faced by other children their age, children with chronic illnesses have to deal with illness-specific challenges, as well as the impact of the illness on functioning in important domains of their life (Wallander & Varni, 1998; LeBovidge et al., 2005). Further, even among children that are faced with similar stressors related to their illness,
differences may exist in psychosocial adjustment based on stress-processing factors such as the child’s attitude toward his/her illness (LeBovidge et al., 2005). Illness perceptions may be defined as the positive or negative judgment of one’s illness, i.e., how one interprets the impact of his/her illness. A child’s feelings about his/her illness may significantly impact how the child copes with and ultimately adapts to the chronic illness (Austin & Huberty, 1993; Austin, Patterson, & Huberty, 1991). For example, children who concentrate on the positive aspects of their illness experience and maintain a positive perspective (e.g., focus on what they can do rather than what they cannot) are more likely to display resilience and engage in adaptive coping skills. In comparison, those children who concentrate on the negative aspects of their illness experience and maintain a negative perspective (e.g., believe their illness makes them different from others or keeps them from achieving their goals) are more likely to internalize their problems and engage in maladaptive coping behaviors (Austin, Patterson, & Huberty, 1991; Austin & Huberty, 1993; Heimlich et al., 2000; LeBovidge et al., 2005).

**Perceived Disease Severity.** The clinical onset of T1DM is usually manifested by hyperglycemia and a number of associated symptoms including, excessive thirst, frequent urination, fatigue, etc. (Atkinson and Esinbarth, 2001). The key to the management of this chronic illness is maintenance of normal levels of metabolic control and prevention and delay of serious and common health complications (e.g., hypoglycemia, nephropathy, neuropathy, retinopathy, diabetic ketoacidosis, etc.) (La Greca & Mackey, 2009). Hypoglycemia is usually accompanied by embarrassing, unpleasant and sometimes potentially dangerous symptoms and thus, causes significant anxiety and fear in adolescents as well as their caregivers (Clarke et al., 2009). Further, hypoglycemia is associated with a reduction in quality of life and reduced
productivity among people with T1DM (Fidler, Elmelund Christensen & Gillard, 2011). The association between HRQoL and glycemic control has been assessed in a large number of studies (Hesketh, Wake, & Cameron, 2004; Hoey et al., 2001; Hassan et al., 2006; Lawrence et al., 2012; Wagner, Müller–Godeffroy, von Sengbusch, Häger, & Thyen, 2005). Across majority of these studies, poor glycemic control has been found to be associated with poor HRQoL. The presence and frequency of diabetes-related complications, especially hypoglycemia, as well as the extent to which normal metabolic control levels are maintained can impact adolescents’ perception of the severity of their diabetes. Based on the aforementioned discussion, the following relationship was hypothesized:

**H1:** Adolescents’ perceived disease (i.e., T1DM) severity will be negatively related to their self-reported HRQoL.

**Perceived Stress.** Adolescents face a number of challenges and transitions, including investment in peer and romantic relationships as well as shifts in family relationships, changes in school and puberty (Graber & Sontag, 2004). Each of these has the potential to become a source of stress in an adolescent’s daily life. Research has demonstrated that such stressful life events are associated with negative health outcomes among adolescents, including depression and anxiety, self-esteem issues, and other behavioral problems (Byrne & Mazanov, 2003; Stevens, Murphy, & McKnight, 2003). Incidence of a severe chronic illness like T1DM can be considered a critical life event and is often perceived as stressful because the disease is unpredictable and a challenge to manage (Seiffge-Krenke & Stemmler, 2003).
Studies have shown that children with high life stress tend to have worse glycemic control (Hains et al., 2007; Hanson & Pichert, 1986). Diabetes-specific stress has also been linked to poor glycemic control (La Greca & Bearman, 2002). Among adolescents with T1DM, stress plays an important role as it can have an impact on the adolescent’s metabolic control in two different ways. Stress can exacerbate metabolic control by a direct impact on adolescents’ physiological functioning (Hanson, Henggeler & Burghen, 1987). Alternatively, it can have an indirect effect on metabolic control by detracting from self-care behavior (Goldston, Kovacs, Obrosky & Iyengar, 1995). Further, studies suggest that adolescents who worry more about their diabetes tend to show poorer metabolic control (Farrell et al., 2004).

Coping has been defined as a process of managing stressors (e.g., internal and external demands) (Seiffge-Krenke & Stemmler, 2003). Hanson and Pichert (1986) studied adolescents at a diabetes summer camp and found that perceived stress and perceived ability to cope were significantly correlated with blood glucose levels. Coping with the demands of self-management of T1DM in adolescence can be a formidable task as this includes both the physical demands of management as well as the emotional and social demands of adjustment (Grylli et al., 2005). Grey and colleagues (2000) used quality of life and metabolic control as outcome markers in order to evaluate the effects of coping skills training (CST) in youth receiving intensive diabetes management (Grey et al., 2000). They found that adolescents who received CST had significantly better metabolic control and less impact on their quality of life in comparison to youth that did not receive CST. Another study examined coping strategies used by adolescents in response to diabetes-related stressors and explored how coping strategies impacted their resilience (quality of life and metabolic control). They found that coping strategies such as
problem solving, emotional expression, acceptance, etc. were associated with better metabolic control and better quality of life in these adolescents with T1DM (Jaser & White, 2011).

Thus, it is conceivable that adolescents that perceive less stress and cope more effectively with their diabetes on a daily basis will demonstrate better health outcomes. Although a number of studies have demonstrated the negative impact of stress on metabolic control, no study to date has analyzed the impact of perceived stress on the HRQoL of adolescents with T1DM. Based on the aforementioned discussion, the following relationship was hypothesized:

\[ H_2: \text{Adolescents’ perceived stress regarding having T1DM will be negatively related to adolescents’ self-reported HRQoL.} \]

**Perceived Diabetes-specific Parental Involvement.** Involvement (in family relationships), as defined by Skinner, Steinhauer, & Sitarenios (2000), is the quality and the degree of interest family members have in each other’s lives. The level of such involvement can either hinder or help in the completion of a task. A study conducted by Berg et al. (2008) in a diabetic population characterized involvement as the person (parent or child) responsible for carrying out various tasks related to the condition. Anderson et al. (1997) suggested that continued parental involvement in diabetes-related tasks may help avoid the deterioration in adherence and metabolic control observed during adolescence. They based this suggestion on developmental theories that emphasize the need to focus on the importance of interdependence in the parent-adolescent dyad for healthy development of the adolescent. Other studies have also reported similar findings. Adolescents were found to exhibit poor metabolic control when diabetes-management responsibilities were not assumed by anyone in the family (Lewin et al.,
Further, those adolescents that demonstrated optimal metabolic control were more likely to have parents that were involved in their diabetes-related tasks (Gowers, Jones, Kiana, North, & Price, 1995). While continued parental involvement in diabetes-related tasks has been associated with better diabetes-related outcomes, research has demonstrated that negative health outcomes could ensue as a result of overly intrusive parenting (Nansel et al., 2009). Thus, it is important that parents remain continually involved in diabetes-related tasks in ways that are perceived to be constructive and helpful rather than counterproductive.

Collaborative responsibility for diabetes-related tasks has been demonstrated as an influential factor affecting diabetes-related health and psychosocial outcomes. A study found that adolescents had better adherence when both the parent and the adolescent reported the responsibility as shared; low shared responsibility (i.e., either one from the adolescent-parent dyad assumed more sole responsibility for the diabetes-related task) resulted in poor glycemic control (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008). Adolescent perceptions of enjoying shared responsibility have also been related to positive diabetes-related outcomes (i.e., adherence and glycemic control) (Berg et al., 2008; Wiebe et al., 2005). Further, higher collaborative involvement between parents and youth with T1DM has been associated with fewer depressive symptoms (Wysocki et al., 2009). Lastly, studies have also explored how glycemic control may be affected by discrepancies in adolescents’ and parents’ views of diabetes-related responsibility. They found that greater levels of discrepancy in parent and adolescent views of diabetes-related responsibility (i.e., diabetes-specific family conflict) were associated with higher HbA1c values (i.e., poorer glycemic control) among these adolescents (Anderson et al., 2002; Cameron et al., 2008; de Wit, Delemarre-van de Waal, Bokma, Haasnoot, Houdijk, Gemke, & Snoek, 2007; Lewandowski, & Drotar, 2007).
In a study among youth with T1DM, higher diabetes-specific family conflict was found to be associated with lower overall quality of life (Laffel et al., 2003). A study by Weissberg-Benchell et al. (2009) found that parents who demonstrated a collaborative style of involvement in their child’s diabetes care had children who reported better HRQoL. Further, families that communicated in a negative fashion regarding diabetes-related issues and reported engaging in more conflict around these issues had children with less than optimal HRQoL. Graue, Wentzel-Larsen, Hanestad & Søvik (2005), Nansel et al. (2009) and Wysocki et al. (2009) reported similar findings regarding the association between parental involvement and HRQoL. Based on the aforementioned discussion, the following relationship was hypothesized:

**H3: Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be positively related to adolescents’ self-reported HRQoL.**

Low levels of family support and family conflict have been found to be associated with poor psychosocial adaptation (Grey et al., 2009). On the other hand, parental guidance, warm and caring family behaviors, open communication, and expression of feelings have demonstrated protective effects on metabolic control and psychosocial adjustment (Grey et al., 2001). When close relationship partners such as parents are perceived as being actively engaged in coping with a chronic illness such as T1DM, the ability to deal with stressful life events among affected adolescents is enhanced (Berg et al., 2009). Thus, parental care and involvement are important factors that can facilitate adolescents’ ability to cope with the everyday demands of T1DM (Graue, Wentzel-Larsen, Hanestad & Søvik, 2005).

The parenting style of one or both parents may impact the diabetes-related self-care behaviors of adolescents with T1DM. Adolescents whose parents/caregivers exhibit
authoritarian, or very strict parenting styles, often report higher stress and poorer metabolic control (Hanna & Guthrie, 2001). Those adolescents whose caregivers exhibit permissive caregiving report lower stress but poor metabolic control. A balance of rule setting and granting freedom, often referred to as authoritative caregiving, yields the most positive results. Adolescents with authoritative caregivers report lower stress and better glycemic control than control groups (Céspedes-Knadle & Muñoz, 2011). Certain caregiver behaviors have been shown to promote or inhibit self-management behaviors in diabetic adolescents. Directive behaviors, such as nagging, scolding, judging, checking, confronting, and getting emotional, were associated with higher adolescent stress and poorer metabolic control. Non-directive behaviors, such as fostering responsibility, reminding, and granting freedom, were associated with lower adolescent stress and greater metabolic control (Dashiff et al., 2011). Based on the aforementioned discussion, the following relationship was hypothesized:

H₄: Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be negatively related to their perceptions of stress.

Perceived Diabetes-specific Peer Support. Adolescents spend most of their waking hours with their peers, be it in school, at work or as part of a leisure activity (La Greca et al., 1995). Thus, it is reasonable to assume that adolescent peers can have an influence on each other’s development. As individuals progress from childhood to adolescence, peers tend to take on an increasing amount of importance as a source of social support (Berndt, 1992). Among individuals with diabetes, although diabetes care-related support from parents and other family members remains crucial throughout childhood and adolescence, during adolescent years they
tend to rely more on similar-aged friends for diabetes management-related support and behavioral norms (Wysocki & Greco, 2006). Friends are considered to offer more emotional support and companionship in comparison to the practical support offered by family members with respect to diabetes management (La Greca et al., 1995 and Skinner, John & Hampson, 2000b).

An increasing amount of attention is being paid to social support from friends as a factor that contributes to adolescents’ self-management of diabetes, given the developmental challenges of adolescence and the increasing importance of friends during this stage. In order to glean the total benefit of positive support offered by friends and prevent any inadvertent interference in their management of diabetes, it is vital that adolescents first reveal their diagnosis to their peers (Wysocki & Greco, 2006). In 1986, Jacobson et al. found that majority of the children and adolescents that were newly diagnosed with T1DM did not discuss their diabetes with their friends and about a third of them believed that their friends would like them less if they learned about their diagnosis (Jacobson et al., 1986). However, in a more recent longitudinal analysis, Greco et al., 2003 found that 64% of the adolescents had revealed their diagnosis to at least one friend during their initial hospitalization and 98% had done so by 3 months following their initial diagnosis. Additionally, they noted that adolescents who planned on withholding their diagnosis from at least one friend had poorer adjustment and lower rates of adherence as compared to those adolescents that did not plan on withholding this information. Once the diagnosis of diabetes is revealed to friends, the possibility of friends’ supportive involvement in diabetes management exists.

Although some studies have found peer support to be related to improved health-related outcomes in adolescents with T1DM, the research is equivocal and others have not found these
associations. Thomas, Peterson, & Goldstein (1997) reported that adolescents with T1DM are more likely to opt for actions that are consistent with their peers’ expectations, thus choosing behaviors that are less regimen adherent. La Greca et al., 1995 noted that support from friends was a protective factor for adolescents with diabetes. Bearman and La Greca (2002) reported that although perceived friend support was not related to overall treatment adherence, it was related to adherence for blood glucose testing. Greco and colleagues found that support from a best friend was perceived as beneficial for diabetes management by adolescents (Greco, Pendley, McDonell, & Reeves, 2001). Pendley et al. (2002) noted that although adolescents may perceive their friends as being helpful with regards to their diabetes regimen, this may be limited based on the availability of their friends and the specificity of the type of support being offered by their peers. Hains et al. (2007) examined the relationships between peer reactions to diabetes management and metabolic control. Adolescents experienced increased difficulty in adhering to their regimen when their friends had negative reactions to their diabetes and diabetes-related management which in turn was associated with poorer metabolic control. Using qualitative interviews, Lowes et al. (2007) found that teenagers with T1DM perceived friends as being usually supportive, looking out for ‘hypos’ and encouraging insulin administration and glucose monitoring. Helgeson, Lopez, and Kamarck (2009) reported that conflict with friends produced greater depressive symptoms and poorer metabolic control among adolescents with T1DM. Thus, peer relationships acted more as a risk factor for poor control than a resistance factor protecting from deterioration in metabolic control.

Although the relationships between friend support and adherence and metabolic control have been demonstrated in the literature (albeit with mixed results), currently limited understanding exists regarding the impact of diabetes-related peer support on adolescents’
HRQoL. This relationship will be examined in this study. Due to previous contradictory findings related to diabetes-related peer support and various health outcomes (e.g., adherence and metabolic control), we are unclear whether diabetes-related peer support will predict positive improvements in HRQoL. The following relationship was hypothesized nonetheless:

**H5: Adolescents’ perceived diabetes-specific peer support will be positively related to their self-reported HRQoL.**

Adolescents who make negative attributions about expected friend reactions to their self-management of diabetes are more likely to anticipate adherence difficulties. These anticipated difficulties are associated with increased diabetes-related stress, which in turn is related to poorer metabolic control (Hains et al., 2006). Bearman and colleagues reported in their study that adolescents with higher stress levels did not employ the use of peer support as frequently as adolescents who reported less stress (Bearman & LaGreca, 2002). Hains et al. (2007) examined the relationships between peer reactions to diabetes management and diabetes-related stress and found that diabetes-related stress increased as friend support increased. A possible explanation for this paradoxical finding is that the support provided by friends maybe maladaptive in nature, encouraging adolescents to make poor behavioral decisions. Additionally, the study found that teens with higher diabetes stress did not effectively use coping mechanisms and viewed peer support adversely.

A qualitative study by Peters and colleagues found that adolescents with diabetes identified various supportive behaviors of friends, particularly concerning emotional support: treating them normally, showing interest, having fun, providing a distraction, and taking their diabetes into account (Peters, Nawijn & Kesteren, 2014). Thus, it conceivable that these
adolescents would perceive a decreased amount of stress given the support they experience from their peers. However, the study also indicated that adolescents hesitated to ask for more support because of the fear of the stigmas attached to the illness and helplessness. Adolescents were afraid of coming across as nagging or needy, were worried about being a burden or felt the need to be autonomous or just treated normally. Thus when attempting to meet and balance these social expectations with their own personal needs, the adolescent may experience an increased amount of stress.

Although increasing attention is being paid to the potentially positive contribution of social support from friends with respect to adolescents’ self-management of diabetes and their perceptions of stress, the evidence remains limited and the results so far have been mixed. As a result, we are unclear whether diabetes-related peer support will reduce adolescents’ perceptions of stress. The following relationship was hypothesized nonetheless:

\[ H_6: \text{Adolescents’ perceived diabetes-specific peer support will be negatively related to their perceptions of stress.} \]

**Self-efficacy for Diabetes Management.** In the context of T1DM, self-efficacy may be conceptualized as the child or adolescent’s confidence in his/her ability to handle diabetes-related tasks (e.g., blood glucose monitoring and reporting, adjusting insulin dosage based on diet and physical activity, etc.) and other situations related to the condition. According to Social Cognitive Theory (Bandura, 1986), those adolescents who have a strong sense of self-efficacy are more likely to be resilient, and to persevere and succeed when faced with barriers related to diabetes self-management. A number of studies in the extant literature have reported a positive
association between self-efficacy and glycemic control as well as diabetes self-management (Griva et al., 2000; Iannotti et al., 2006; Johnston-Brooks, Lewis, & Garg, 2002; Ott et al., 2000). Grossman, Brink, and Hauser (1987) reported significant relationships between beliefs about diabetes self-efficacy and perceptions of control as well as self-esteem in a sample of adolescent boys and girls with TIDM.

Studies in adolescents with T1DM have documented a positive relationship between self-efficacy and HRQoL (Grey et al., 1998, 2001). Additionally, researchers have posited that improving adolescents diabetes-related coping skills may increase their perceptions of self-efficacy and this in turn may facilitate physiological and psychosocial adaptation to their condition (Grey et al., 2000). They found that coping skills training did in fact improve adolescent self-efficacy as well as metabolic control and quality of life. Based on the aforementioned discussion, the following relationship was hypothesized:

**H7: Adolescents’ self-efficacy for diabetes management will be positively related to their self-reported HRQoL.**

**Diabetes Summer Camps**

Adolescents with chronic illnesses such as T1DM have both physical and emotional needs that surpass those of adolescents without chronic illnesses. Social support has been found to play an important role in the adjustment of children and adolescents living with T1DM, with increased support usually being associated with better illness management and physiological and psychosocial adjustment (Wallander and Varni, 1992).
Summer camps have been shown to be a supportive and beneficial environment for youth, especially for children and adolescents facing a variety of medical conditions (Winfree, Williams, & Powell 2002). With T1DM being considered one of the most psychologically and behaviorally demanding chronic illnesses facing adolescents (Cox & Gonder-Fredrick 1992), there is tremendous potential for camps to positively impact the lives of affected adolescents. The camp environment provides an ideal setting to closely monitor blood glucose, insulin dose and carbohydrate intake in adolescents with T1DM. Further, these summer camps can provide an environment where affected adolescents can learn positive coping skills and strategies; engage in fun-filled, age appropriate experience where they can acquire activity-related skills; develop a self-sufficient attitude; enhance their self-esteem; develop a sense of mastery and efficacy in peer relationships; and help children learn about their illness either through formal education, or informal peer interaction (Kiernan, Gormley & MacLachlan, 2004). Adolescents can take the skills and confidence gained in the camp setting and apply the same to their normal environment at home. Being in the safe environment of a camp in the company of others like themselves, adolescents may realize that they are not alone in their fight against their condition and that they can accomplish tasks that they previously thought impossible. Thus, such camps are an effective means to train youths and help them adopt a healthy attitude toward their condition.

A study conducted among various medical personnel on diabetes teams reported that these personnel perceived a difference in the typical child that attended diabetes camp on attitude and self-efficacy in comparison to the typical child who did not attend camp. According to these diabetes team members, attending camp was associated with more positive attitudes and greater self-efficacy, which can potentially positively impact self-management of the disease (Timmons, 2009). Based on the aforementioned discussion, in the present study we expect differences in
perceptions to exist between diabetes camp and non-camp adolescent participants on their perceived level of stress, their perceived parental involvement and peer support, their ability to manage their condition and their HRQoL.
CHAPTER III

RESEARCH DESIGN AND METHODS

Prior to discussing the design of the proposed research study and the procedures that were utilized to accomplish the research objectives, it is imperative to review certain methodological considerations related to surveying pediatric populations and assessing their HRQoL.

Surveying Pediatric Populations: Methodological Considerations

Survey researchers interested in examining the attitudes, perspectives, and behavior of children are increasingly collecting this information directly from them (i.e., the child is the principal informant) (Borgers, Hox, & Sikkel, 2003). A number of distinctive methodological problems may arise when surveying children and adolescents. Oftentimes when surveying children, they are considered to be miniature adults. This can be problematic since their cognitive, communicative, and social skills are still developing, which in turn impacts their ability to answer questions included in a survey (Borgers, De Leeuw, & Hox, 2000). Each age group (among children and adolescents) has its own set of issues and therefore the design of a survey should be tailored based on the degree of social and cognitive development in the particular group being surveyed.
Research in this area has found that young children (ages 8 – 11 years) may have trouble with negatively phrased questions and have minimal tolerance for ambiguity (Benson & Hocevar, 1985). Further, research has found that the reliability of results obtained when surveying children may be improved by using completely labeled response options (Borgers et al., 2003). Another important aspect survey researchers need to be aware of is that children may tend to utilize satisficing techniques when responding to a survey. This usually occurs when children are unsure of the meaning of the question or they find the topic uninteresting (Borgers, Sikkel, & Hox, 2004). Extremely long and wordy tasks will result in children losing their concentration and motivation to answer questions accurately. Therefore, it is important to ensure that both questions and the accompanying instructions/directions are simply and clearly worded, and are not negatively phrased.

Children between the ages of 11 and 15 years have sufficiently well-developed cognitive functioning. Studies have found that children around the age of 11 years are capable of answering survey questions consistently and this ability improves with age, stabilizing at 14 years (Borgers et al., 2000). The key issues that survey researchers need to guard against in this group are flippancy and boredom, since lack of motivation can adversely affect data quality (Scott, 1997). Providing graphical and visual questions may help alleviate such issues. Children who are 16 years and older are generally treated as standard adults in surveys. However, the social context of the survey (e.g., presence of others, gender and age of interviewer, etc.), in conjunction with the topic has been found to be an important aspect to consider when surveying this group of children (Borgers et al., 2000).

In general, researchers recommend the use of various pretesting methods in order to protect against poor data quality when surveying children. Prior to pretesting the survey in
children, it is important to consult experts in the field to assess face and content validity of the
survey. The next step involves conducting cognitive interviews among a sample of children in
order to evaluate the questionnaire. Such cognitive pretests help the researcher understand which
questions are particularly hard for children in the sample to understand and respond to and why.
Findings from cognitive interviews enable the researcher to make appropriate changes to the
questionnaire prior to fielding the survey in a larger sample.

**HRQoL Assessment in Adolescents: Methodological Considerations**

**Child self-report versus parent-proxy.** Studies assessing HRQoL in pediatric
populations have consistently documented imperfect agreement between child self- and parent-
proxy reports (Varni, Burwinkle, & Lane, 2005). Some studies have documented low agreement
and others have documented high agreement between these reports. As a result of the conflicting
results it is not possible to provide an empirically based, conclusive position on the proxy
question (Matza, Swensen, Flood, Secnik, & Leidy, 2004). HRQoL is not a directly observable
construct and is usually conceptualized and understood as a latent construct. It is subjective in
nature given that it contains perceptions and evaluations of one’s life from the individual’s own
point of view, as well as the individual’s subjective well-being and affective mood (Ravens-
Sieberer et al., 2006). Therefore, whenever a child is capable of providing reliable and valid data,
assessing the child’s HRQoL through self-report is the ideal strategy because it is consistent with
the definition of HRQoL (Matza et al., 2004). Further, using child self-report permits
consideration of the child’s perspective and thus, allows provision of treatment options that will
have the most positive impact in multiple domains of the child’s life (Eiser, Mohay, & Morse, 2000).

A number of disadvantages of using parent-proxy reports have been cited in the literature. First, utilizing parent-proxy reports is inconsistent with the definition of HRQoL, which emphasizes the patient’s subjective perspective. Second, when using this method questions regarding which parent’s (mother or father) assessment of the child’s HRQoL should be utilized arise. Third, parents’ reports of a disease’s impact on their children may be biased in that it may reflect how the parents themselves are affected by the disease. Lastly, in a lot of situations the parents may not be the most appropriate adult proxy respondent as the child may spend more time with other caregivers, including teachers or other family members (Landgraf & Abetz, 1996). Obtaining reports from both the child as well as the parent is an approach that could possibly provide the most complete picture regarding how the disease and/or treatment impacts the child and the family as a whole. However, this approach is more costly as it entails collecting data from both sets of respondents and also raises methodological issues, such as whether data should be pooled or interpreted separately, and whose responses to consider when there is disagreement in the child and parent reports (Matza et al., 2004). For the purposes of this study, data was collected directly from adolescents with T1DM, 11 – 16 years of age.

**Generic versus condition-specific HRQoL measures.** Both types of measures have been developed to assess HRQoL in children and adolescents. Generic HRQoL measurement instruments can be used to compare the impact various diseases have on HRQoL. Additionally, they provide useful benchmarking data, i.e., data from a specific patient population can be compared to general pediatric population norms to determine the impact of the disease on HRQoL. However, generic measures lack certain qualities of condition- or disease-specific
measurement instruments. These disease-specific measures assess symptoms and treatment side effects that are relevant to the particular disease state. Further, they are more sensitive to specific clinical changes and tend to be more effective at detecting treatment effects. However, disease-specific measures cannot be utilized to make comparisons across disease states or with healthy population norms (Matza et al., 2004; Varni et al., 2005).

Based on the aforementioned discussion, for the purposes of this study the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales – Child (Ages 8 – 12) and Teen (Ages 13 – 18) self-reports was utilized to assess HRQoL in adolescents with T1DM. (For details regarding the instrument refer to the section titled ‘Measures’ on pp. 37)

**Study Design**

The study employed a cross-sectional, non-experimental, quantitative design to: (1) examine the impact of various factors (perceived stress, diabetes-specific parental involvement, self-efficacy for diabetes management, and perceived peer support) on adolescents’ self-reported Health-related Quality of Life (HRQoL); (2) assess the association between these factors and their self-reported HRQoL; and (3) determine if differences in perceptions exist between diabetes camp and non-camp adolescent attendees on their perceived level of stress, their perceived parental involvement and peer support, their ability to manage their condition and their HRQoL. Self-administered paper-based surveys were administered to adolescents with T1DM by a member of the research team. Adolescents were recruited from multiple sites in order to increase the size of the responding sample.
Sample Description

The target population for this study is children and adolescents with T1DM between 11 and 16 years of age, inclusive. From here on, child and adolescent participants will be referred to as adolescents, consistent with the view that adolescence encompasses the period from ages 10 through 18 years (Arnett, 2000; Wiebe et al., 2010). Adolescents were recruited from multiple sites, including diabetes summer camps\(^2\), and university clinics\(^3\), and community-based private practices\(^4\), employing a convenience sampling design. Additional eligibility criteria that were utilized in order to recruit adolescents with T1DM for the purposes of this study are as follows --

**Inclusion criteria:** (a) ability to read and speak the English language; (b) living with parent(s) (either one or both); and (c) treatment regimen which involves daily management. **Exclusion criteria:** (a) a major psychiatric or neurocognitive disorder that would limit the adolescent’s ability to complete the survey (e.g. cognitive impairment).

Sample Size

Different authors have provided varying opinions regarding the minimum sample size requirement for structural equation models. Hair and colleagues have recommended a minimum sample size of 200 when using maximum likelihood as the estimation procedure in SEM (Hair, Black, Babin, Anderson, & Tatham, 2006). Kline (2005) noted that in general, a sample size of less 100 is considered ‘small’, those between 100 and 200 are considered ‘medium’, and those

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\(^2\) Existing collaboration with Camp Hopewell, Oxford, MS, Camp Victory, Anacoco, LA, Camp INdependence, Princeton, IN, Camp Endres Senior, Guthrie, OK, and Camp Nejada, Newton, NJ.

\(^3\) Existing collaboration with diabetes clinics at UMMC (Personal communication with Dr. Naznin Dixit - Pediatric Endocrinology, Professor and Director)

\(^4\) Existing collaboration with community-based private practice (Personal communication with Dr. Mark Shepherd in Tupelo, MS, and Dr. Ikhlas Khan in Bartlett, TN).
greater than 200 may be considered ‘large’. The author recommends using the following ratio as a rule of thumb in order to calculate the required sample size: number of cases : number of free parameters : : 10 : 1. In the proposed study model (See Figure 3), there are 16 free parameters (11 regression coefficients, 5 error variances, and 1 residual). Based on the aforementioned recommendation by Kline (2005), the minimum sample size required for this study is 160 adolescents. However, given that a minimum sample size of 200 is generally considered acceptable (Hair et al., 2006; Kline, 2005), data was collected from a minimum of 200 adolescents with T1DM that met the study’s eligibility criteria.

Survey Description

The survey consisted of two parts (Appendix A). Questions related to sociodemographic characteristics of the participating adolescents and questions related to the adolescent’s condition (T1DM) (e.g., number of years with T1DM, type of insulin therapy, etc.) were included in Part 1 of the survey. Part 2 included five measures: (1) Collaborative Parental Involvement (CPI) Scale, (2) Self-Efficacy for Diabetes Management (SEDM) Scale, (3) Perceived Stress Scale (PSS), (4) Diabetes Social Support Questionnaire – Friends version (DSSQ-Friends), (5) Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales.
Measures

**Sociodemographic characteristics and disease-related questions.** Adolescents answered questions related to the following in order to assess their sociodemographic and disease-related characteristics:

1. Age (Open ended)
2. Gender (Male, Female)
3. Race (White/Caucasian, Black/African American, Other, Not sure)
4. Ethnicity (Hispanic/Latino, Not Hispanic/Latino, Not sure)
5. Number of years with T1DM (Open ended)
6. Attendance at a diabetes camp (Yes, No)
7. Number of years adolescent has attended a diabetes camp (Open ended)
8. Type of insulin therapy (Multiple daily injections (MDI), Insulin pump therapy)
9. Frequency of blood glucose checking (Open ended)
10. Effect of diabetes (1 = Not at all and 10 = A great deal)
11. Whether diabetes is under control or not? (Yes, No, Not sure)

Given that physiological adjustment/adaptation (i.e., metabolic control) is difficult to measure in survey-based research and it has been previously explored in the extant literature, in the current study, a self-reported measure of perceived disease severity was utilized. Effect of diabetes (measure 10 above) was used to measure perceived diabetes severity in this study. Respondents were asked to indicate the affect or impact their diabetes had on their daily lives. Thus, this measure provided an account of the responding adolescents’ subjective assessment of their disease severity.
**Collaborative Parental Involvement (CPI) Scale.** A number of measures that assess parental involvement in diabetes management are available in the extant literature. This construct (i.e. parental involvement) has been typically conceptualized as instrumental support provided by the parent (i.e. actual diabetes management assistance) or affective parental support (i.e. availability of and satisfaction with support). The Diabetes Family Responsibility Questionnaire (Anderson, Auslander, Jung, Miller, & Santiago, 1990) is an example of a measure that assesses instrumental support and the Diabetes Family Behavior Checklist (Schafer, McCaul, & Glasgow, 1986) is a measure that addresses a combination of instrumental and affective support provided by the parent in diabetes management. Although the aforementioned (examples of) measures embody various aspects of parental involvement in diabetes management, they fail to assess parental behaviors that reflect a collaborative style of involvement (Nansel et al., 2009).

Given that adolescence is a transitional period that is characterized by a shift in parents’ role from being directive to being more collaborative in nature, it requires parents to adjust the type and level of assistance they provide their child over time during this period. Since the current study’s target population is adolescents with T1DM, a decision to use the Collaborative Parental Involvement (CPI) Scale developed by Nansel et al. (2009) was made. The CPI Scale is a unidimensional, 12-item child self-report measure that seeks the child’s rating of their parents’ level of collaboration in diabetes-related tasks. It specifically measures the *quality* of collaborative involvement by parents in diabetes-related tasks without focusing on the *quantity* of parental assistance (Beléndez, de Wit, & Snoek, 2010; Wysocki et al., 2009). The instructions ask the respondent to indicate if they have a parent who helps them with various tasks and issues related to diabetes management, with the items being scored using a five-point verbal frequency scale (1 = Almost never to 5 = Always). Possible scores on this scale range from 12 to 60, with
higher scores indicating that the youth perceives more collaborative involvement by their parent. The measure has been shown to be reliable (Cronbach’s $\alpha = 0.91$) and valid (Nansel et al., 2009).

**Self-Efficacy for Diabetes Management (SEDM) Scale.** The Self-Efficacy for Diabetes Management (SEDM) Scale was used to assess adolescents’ perceptions of their ability to manage their diabetes across various problematic situations. This scale was selected for the present study because, unlike the Self-Efficacy for Diabetes Scale developed by Grossman et al. in 1987, this scale reflects current diabetes-self management practices (Iannotti et al., 2006). Adolescents respond to the question, “how sure are you that you can do each of the following, almost all the time” for 10 items, with the items being scored using a ten-point linear numeric scale (1 = not at all sure to 10 = completely sure). An average score of the items is calculated for this measure, with higher scores indicating greater perceptions of self-efficacy. Previous work with adolescents with T1DM has shown this measure to be reliable (Cronbach’s $\alpha = 0.90$) and valid (Iannotti et al., 2006).

**Perceived Stress Scale (PSS).** The Perceived Stress Scale (PSS) was used in order to assess the general stress perceived by adolescents with T1DM. It is a measure of the degree to which individuals’ appraise situations in their life as stressful and is the most widely used psychological instrument for measuring the perception of stress (Cohen, Kamarck & Mermelstein, 1983). Items included in the PSS have been designed to ascertain how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of items that assess the current levels of stress experienced by the respondents. The questions in the PSS ask about feelings and thoughts during the last month. In each case, adolescents were asked how often they felt a certain way, with items being scored
using a five-point verbal frequency scale (0 = Never to 4 = Very often). PSS scores are obtained by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. Possible scores on this scale range from 0 to 40, with higher scores indicating that the youth perceives a higher level of stress. The PSS has been shown to be reliable (Cronbach’s α = 0.85) and valid (Cohen, Kamarck & Mermelstein, 1983).

**Diabetes Social Support Questionnaire – Friends version (DSSQ-Friends).** The Diabetes Social Support Questionnaire – Friends version (DSSQ-Friends) was utilized in order to assess adolescents’ perceptions of friends’ support for diabetes care (Bearman & La Greca, 2002). The scale consists of 28 items that are distributed among the following support behaviors: insulin (2 items), blood testing (6 items), meals (13 items), exercise (4 items), and emotional (3 items). Supportiveness for each item is assessed by the question, “how does this make you feel? or how would you feel?” Adolescents rate the degree of supportiveness using a 5-point Likert-type scale (-1 = not supportive, 0 = neutral, 1 = a little supportive, 2 = supportive, 3 = very supportive). Frequency for each item is assessed by the question, “how often do your friends …?” with items being scored using a six-point verbal frequency scale (0 = Never, 1 = less than 2 X a month, 2 = twice a month, 3 = once a week, 4 = several times a week, 5 = at least once a day). Average scores for supportiveness and frequency were calculated across adolescents. Further, ratings for each item were combined multiplicatively in order to calculate a combined score. This combined score thus takes into account both the frequency and supportiveness of each behavior as perceived by the adolescent and can range from -5 (unsupportive behavior that occurs frequently) to 15 (very supportive and very frequent behavior). Again, combined scores
were calculated for each item and averaged across adolescents. The DSSQ - Friends has been shown to be reliable (Cronbach’s $\alpha = 0.70$) (Bearman & La Greca, 2002).

**Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales.**

Adolescents’ HRQoL was assessed using the 23-item PedsQL 4.0 Generic Core Scales which encompass (a) Physical Functioning (8 items), (b) Emotional Functioning (5 items), (c) Social Functioning (5 items), and (d) School Functioning (5 items). These items have been developed through numerous patient and parent focus groups, cognitive interviews, pre-testing, and subsequent field testing following standardized protocols (Varni, Burwinkle, Seid, & Skarr, 2003; Varni & Limbers, 2009). The PedsQL 4.0 Generic Core Scales is comprised of parallel child self-report and parent proxy-report formats. For the purposes of this study, only the child self-reports -- ages 8–12, and 13–18 years -- was utilized. The items in both these forms are essentially identical, the only difference being in the utilization of developmentally appropriate language.

The instructions ask how much of a problem each item has been during the past 1 month, with the items being scored using a five-point verbal frequency scale ($0 = \text{never a problem}, 1 = \text{almost never a problem}, 2 = \text{sometimes a problem}, 3 = \text{often a problem}, \text{and} 4 = \text{almost always a problem}$). Items are reverse scored and linearly transformed to a 0–100 scale ($0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0$), higher scores being indicative of better HRQoL. The scores for each subscale are computed as the sum of the items divided by the number of items answered. If more than 50% of the items in the scale are missing, the scale score is not computed (Varni et al., 2003). Although different strategies for imputing missing values are available, this computation is consistent with other PedsQL peer-reviewed publications (Varni, Seid, & Rode, 1999; Varni, Seid, & Kurtin, 2001; Varni et al., 2003). To create the ‘Total Quality of Life Score’ (or Total
Scale Score), the mean is computed as the sum of all the items over the number of items answered on all the Scales. The Physical Health Summary Score (8 items) is the same as the Physical Functioning Subscale. To create the Psychosocial Health Summary Score (15 items), the mean is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Subscales (Varni, 1998-2013). The measure takes about 5 minutes to complete and has been shown to be reliable (Cronbach’s $\alpha = 0.89$, child self-report) and valid (Varni et al., 2003).

**IRB Approval**

The study’s procedures were reviewed and approved by the Institutional Review Boards (IRB) at the University of Mississippi, Oxford, MS, and the University of Mississippi Medical Center, Jackson, MS. Further, the study’s procedures were approved by participating diabetes summer camps’ review teams as well as by applicable personnel (e.g., pediatrician, endocrinologist, pediatric endocrinologist, etc.) in the collaborating community-based private practices.

**Field Pretesting**

A focus group discussion was conducted among fourteen adolescents attending the Diabetes Youth Council Retreat at Camp Hopewell in Oxford, MS, by a member of the research team in order to understand adolescents’ views toward their diabetes, how they manage their
diabetes and the impact of diabetes on their day to day life. This session also helped identify potential problems with wording, ordering and formatting of questions included in the survey.

Participants were asked to rank the factors that had the most influence on the way they approached their diabetes. Five factors (the severity of your diabetes, the type of insulin therapy you use, the confidence in your ability to manage your diabetes, the number of years you have lived with your diabetes, your parents’ involvement with handling your diabetes) were selected based on the review of the literature. Participants cited ‘the confidence in their ability to manage their diabetes,’ as the number one factor followed by ‘their parents’ involvement with handling their diabetes’ as the second most important factor that influences the way they approach their condition. Two factors that were not included in the ranking task and that participants repeatedly noted during the discussion were, diabetes as a ‘stressor’ in their daily lives and the importance of support from peers (especially those that have T1DM) in managing their diabetes.

Further, the interviewer also specifically evaluated the following issues: (a) the adolescent’s ability to understand and respond to items rated on the various types of scales included in the survey; (b) the adolescent’s opinion regarding the formatting of the survey; and (c) the adolescent’s ability to independently complete the survey (Matza et al., 2004). Participants approved of the formatting of the survey items and in general were able to independently respond to the survey. Additionally, all the participants were able to understand and respond to the sample survey items using the different scales that were presented to them. Based on the input received during the focus group, necessary changes were made to the survey instrument.
Data Collection

**General procedure.** *(a) For adolescents with T1DM who receive treatment at the university clinic or community-based private practice:* The attending nurse practitioner, pediatric endocrinologist and/or a member of the research team briefly described the study to parents of children who have T1DM during their clinic visit and determined the adolescents’ eligibility to participate in the study. Clinic personnel and/or a member of the research team solicited written consent from the parents of eligible adolescents, followed by assent from the adolescents themselves (For a copy of the consent and assent forms, see Appendix B). Parents and their child had the opportunity to review details about the study (study flyer and information sheet were provided by clinic personnel and/or a member of the research team) (Appendix B), understand his/her rights as a participant of this research, and an opportunity to contact the researcher or IRB directly regarding any questions or concerns they have related to the study. Those parents and adolescents that agreed to participate were requested to complete the consent and assent forms as well as the self-administered paper-based survey instrument in the waiting room of the pediatric clinic. On average, the survey took no longer than 30 minutes to complete.

*(b) For adolescents with T1DM attending a diabetes summer camp:* Adolescents attending the various aforementioned diabetes summer camps were recruited to participate in the study. The respective camp registrars emailed study materials, including study flyer and information sheet as well as the parental consent form to parents of adolescents that planned on attending their summer camp. The camp registrar did not recruit subjects for this study. The aforementioned documents were mailed to the parents through the camp in advance to allow
parents the opportunity to review details about the study along with their child, understand his/her rights as a participant of this research, and to give them the opportunity to contact the researcher or IRB directly regarding any questions or concerns they have related to the study. The parent had the opportunity to consent to their child’s participation in the study via email. When a parent did not consent via email, a member of the research team solicited their written consent at the time of camp check-in.

Participating adolescents (of consenting parents) were required to sign the assent form prior to participation in the study at the respective camp locations. Those adolescents who gave their assent to participate were surveyed at the camp location. Adolescents completed the self-administered paper-based survey instrument during the first 48 hours of camp. On average, the survey took no longer than 30 minutes to complete. The survey was administered in a group setting during camp hours and did not interfere with planned camp activities. A member of the research team was present to answer any questions related to the survey or study in general. A copy of the study materials including, study flyer, study information sheet, parental consent form, adolescent assent form are available in Appendix C.

Extensive efforts were made to ensure that the participants and their families did not feel coerced to participate in the study. They were informed that their participation is voluntary and choosing not to participate would not affect their child’s current or future relationship with the diabetes clinic (diabetes camp) or any personnel (e.g., physicians, nurses, camp staff, etc.) affiliated with the diabetes clinic (diabetes camp). Further, they were assured of anonymity as well as the confidentiality of the data.
Data Management

Cursory sight-editing of the completed surveys was carried out to ensure that the surveys received were largely usable (i.e. contain minimal missing data). This helped prevent premature termination of the data collection process. Each survey instrument was assigned a unique identification number based on the order of its receipt. Data were double-entered into the Data Editor (.sav) of the IBM SPSS Statistics v21.0 software package by a member of the research team. The datasets were checked to ascertain if any discrepancies exist (i.e., non-comparable entries) as a result of human error during data entry using the Compare Datasets function available in the Data menu. Any existing discrepancies were investigated and rectified. Next, those items that are reverse coded in the survey instrument were recoded prior to data analysis. Further, each variable was checked to ensure that the data were within the permissible range by generating a frequency distribution for the variable (i.e. wild-code checking) (Singleton & Straits, 2005). The datasets were checked for missing data and those respondents with significant portions of the survey incomplete (> 15%) were excluded from the study (Acuna & Rodriguez, 2004). Lastly, an EM-based (Expectation Maximization) approach for handling missing data was utilized in order to impute missing data, using AMOS v20.0 (Allison, 2003; Byrne, 2001).

Nonresponse Bias

Nonresponse bias is said to exist when people who respond to the survey are found to differ substantially from those people that did not respond to the survey, in terms of sociodemographic characteristics or some other variables of interest (Armstrong & Overton, 1977; Dillman, Smyth, & Christian, 2009). One of the methods of estimating nonresponse bias is
to compare ‘early’ and ‘late’ responders on various variables, given that ‘late’ responders are theorized to be more like (similar to) nonrespondents (Armstrong & Overton, 1977). Since we surveyed adolescents with T1DM either (i) all at once at a diabetes camp or (ii) based on their next scheduled clinic appointment, the utilization of this method to estimate nonresponse bias was not be possible. Another method of estimating nonresponse bias is to compare the results from a survey with ‘known’ values (e.g., age, gender, and race) for the population (Armstrong & Overton, 1977). At this time no access to such data was granted, even if available.

**Data Analyses**

Given that the maximum likelihood estimation (MLE) technique utilized in SEM assumes multivariate normality, the data were screened in order to assess if the assumptions of multivariate normality are met. In order to ascertain if the univariate distributions are normal, individual variables were evaluated by checking absolute values of skew and kurtosis indexes. Variables with absolute values of the skew index > 3.0 and kurtosis index > 10.0 were considered extreme and warrant examination (Kline, 2005). Multivariate normality was assessed using Mardia’s coefficient of multivariate kurtosis. Data can be considered multivariate-normally distributed at the 0.05 level of significance when the critical ratio of Mardia’s multivariate kurtosis is less than 1.96 (Gao, Mokhtarian, & Johnston, 2008). Outliers are also considered as violations of normality. Multivariate outliers were detected based on the value of their Mahalonobis distance (Kline, 2005). The larger this distance (i.e., higher Mahalonobis distance values), the larger is the contribution of the outlier to departures from multivariate normality, thus warranting its examination (Gao et al., 2008). Linearity is also an aspect of multivariate normality that was examined by inspection of bivariate scatterplots (Kline, 2005).
Section I: Descriptive Analyses

A description of the responding sample is provided by reporting means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Independent samples t-test was utilized to compare various scale scores obtained from the adolescents attending a diabetes summer camp with those obtained from adolescents that have never attended a diabetes summer camp (Responses collected from either the university or community-based diabetes clinics).

Section II: Model Testing

The approach outlined by Anderson and Gerbing (1988) was utilized in order to test the proposed study model and examine the relationships hypothesized therein (See Figure 3). This approach will test the fit and construct validity of the measurement model and will involve assessing the structural model.

**Fit and construct validity of the measurement model.** HRQoL is the only variable that was modeled as a latent variable. Subscale scores (i.e., Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning) on the PedsQL 4.0 Generic Core Scales served as the indicators for the latent variable (HRQoL). Measurement properties of the latent construct (HRQoL) were examined using CFA (Anderson & Gerbing, 1988). As mentioned earlier, model identification is an important step in CFA. The aim is to specify a model that is ‘overidentified’ (Byrne, 2001). With p observed variables, there are:

\[
\text{No. of data points} = \frac{p (p + 1)}{2} = \frac{[4 (4 + 1)]}{2} = 10 \quad \text{(in this assessment of HRQoL)}
\]

\[
\text{No. of estimable parameters} = 4 \text{ loading estimates} + 4 \text{ error variances} = 8
\]
The resulting model had $10 - 8 = 2$ degrees of freedom (df), and was thus, an overidentified model (Hair et al., 2006).

Maximum likelihood estimation was used for parameter estimation in the CFA. Model fit was assessed using a number of different model fit indices including the chi-square goodness of fit statistic--$\chi^2$, Bentler’s comparative fit index (CFI), and root mean square error of approximation (RMSEA). The following criteria were used to assess model fit: CFI $> 0.95$ and RMSEA $\leq 0.06$ (Hu & Bentler, 1999). Next the individual factor loadings were examined. High loadings on a factor indicate that they all converge on some common point, depicting high convergent validity. As a rule of thumb, Hair et al. (2006) suggest that standardized loading estimates should be $\geq 0.5$ and ideally $0.7$ or higher. Reliability is also an indicator of convergent validity. Internal consistency exists when a construct has high reliability estimates, i.e., the measures (or indicator variables) all consistently represent the same latent construct (Hair et al., 2006). Cronbach’s alpha reliability estimates were calculated for the construct (i.e., HRQoL).

In general, values of $\geq 0.70$ for Cronbach’s alpha are considered to represent acceptable reliability (Hair et al., 2006).

**Structural model and hypothesis testing.** On obtaining a satisfactory measurement model, the structural model was examined next using SEM. The structural model was specified using a path diagram (See Figure 3). It contains one latent variable (HRQoL) and nine observed or measured variables (disease severity, diabetes-specific parental involvement, self-efficacy for diabetes management, perceived stress, diabetes-specific peer support, physical functioning, emotional functioning, social functioning, and school functioning). Calculations for model identification are as follows:
Figure 3. Measurement and Structural Model
With $p$ observed variables, there are:

No. of data points $= p (p + 1) / 2 = [9 (9 + 1)] / 2 = 45$

No. of estimable parameters $= 11$ regression coefficients + 5 error variances + 1 residual $= 17$

The resulting model has $45 – 17 = \textbf{28 degrees of freedom}$ (df), and was thus, an overidentified model (Hair et al., 2006).

Maximum likelihood estimation (MLE) was utilized in order to test the structural model. Model fit was assessed using the following fit indices: $\chi^2$, CFI (values $> 0.95$) and RMSEA ($\leq 0.06$). Standardized parameter estimates obtained from the SEM analysis were used to test the previously stated hypotheses. Standardized residuals and modification indices are the diagnostic measures that were utilized in order to determine if model re-specification was needed. Although model re-specification can improve fit, these diagnostic measures were explored and considered from a theoretical rather than data driven perspective (Hair et al., 2006; Standage & Gillison, 2007).

**Mediation analyses:** A single model that includes the hypothesized mediated paths was tested. For each hypothesis, the proposed mediated relationship was compared with the alternative model and the change in chi-square value was examined in order to determine the best-fitting model (Hair et al., 2006).

All analyses (Step 1 and Step 2) will be conducted using AMOS v20.0. All hypotheses will be tested at a significance level of 0.05 (i.e., p-value $\leq 0.05$).
CHAPTER IV

RESULTS

A total of 327 survey responses were collected from T1DM camps and clinics. Each of the surveys was assigned a unique identification number based on the order of its receipt. The data were checked to ascertain if any discrepancies exist (i.e., non-comparable entries) as a result of human error during data entry using the Compare Datasets function available in the Data menu in SPSS. Identified discrepancies were investigated and rectified. Next, those items that are reverse coded in the survey instrument were recoded and each variable was checked to ensure that the data were within the permissible range by generating a frequency distribution for the variable. The dataset was also checked for missing (> 15% missing per survey) or incomprehensible data. Thirty-six such survey responses were excluded due to incomplete or incomprehensible data. A final sample of 291 responses was included for study analysis.

Assumption Testing

Given that the maximum likelihood estimation (MLE) technique utilized in SEM assumes multivariate normality, the data were screened in order to assess if the assumptions of multivariate normality were met. Univariate distributions of the data were considered to be
non-normal if the result of dividing skewness and kurtosis scores by their respective standard errors was greater than ±1.96. Further, Kolmogorov-Smirnov (K-S) and the Shapiro-Wilk (S-W) tested the sample for a normal-distribution. Both test the null hypothesis that the data come from a normally-distributed population. The alternate hypothesis is therefore that the data come from a population that is not normally distributed. Consequently, if the results of either test are significant (i.e., p < 0.05) rejecting the null hypothesis means rejecting the assumption of normality for the distribution. Based on this, perceived stress was the only study variable that had a univariate normal distribution (See Tables 1 and 2). Multivariate normality was assessed using Mardia’s coefficient of multivariate kurtosis. Data can be considered multivariate-normally distributed at the 0.05 level of significance when the critical ratio of Mardia’s multivariate kurtosis is less than ±1.96. Given that the critical ratio of Mardia’s multivariate kurtosis for the study sample was 6.557, the data are multivariate non-normal.

A curve estimation was performed for all the relationships in the study model and it was determined that all relationships were sufficiently linear to be tested using a covariance-based SEM algorithm such as the one utilized in AMOS. Further, multicollinearity was examined by calculating variance inflation factor (VIF) and tolerance. Values of VIF > 3 and tolerance < 0.10 were considered to be indicative of significant multicollinearity between the predictor variables. In the current study sample, all predictor variables had VIF values < 3 and tolerance values > 0.10, respectively indicating that little or no multicollinearity exists between the predictor variables.
Missing Data Imputation

Since the data were found to be multivariate non-normal, bootstrapping had to be performed in AMOS to appropriately analyze the data. In order to perform bootstrapping in AMOS the data are required to have no missing values. An EM-based approach for handling missing data was utilized in order to impute missing data for the study variables and thus have a complete dataset for bootstrapping.

<table>
<thead>
<tr>
<th>Table 1: Study Variables – Skew and Kurtosis</th>
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<tbody>
<tr>
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<tr>
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<td>Self-Efficacy</td>
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<td>Perceived Stress</td>
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<tr>
<td>DSSQ – Multiplicative</td>
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<td>Physical Functioning – QOL</td>
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<td>Emotional Functioning – QOL</td>
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<td>Social Functioning – QOL</td>
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<td>School Functioning – QOL</td>
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Table 2: Study Variables – Tests of Normality

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<td>School Functioning – QOL</td>
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Descriptive Statistics

Characteristics of the responding sample are depicted in Table 3. The mean age of the adolescents with T1DM in the study sample was approximately 13.5 years (SD 1.5) with the range being 11 to 16 years. Majority of the participants were female (59.5%), white (75.1%), and not Hispanic/Latino (66.1%). The mean number of years the adolescents in the sample had lived with T1DM was approximately 5.5 years (SD 3.5). Majority of the participants had attended a diabetes summer camp at least once in their life (81.4%), with the mean number of years having attended such camps being approximately 3 years (SD 2.5). Further, majority of the adolescent participants used insulin pumps (68.2%) as part of their daily insulin therapy and perceived their diabetes to be under control (65.6%).

Descriptive statistics for the various scales included in the study are depicted in Table 4. The mean score on the quality of life physical functioning scale was 87.4 (SD 13.5), emotional functioning scale was 76.7 (SD 19.7), social functioning scale was 87.5 (SD 14.8), and school functioning scale was 75.7 (SD 17.8), respectively. Overall, the responding sample reported that
their diabetes has a moderate impact on their daily life (Mean = 5.4 (SD 2.4)), perceived significant collaborative involvement by their parent(s) in managing their diabetes (Mean = 49.4 (SD 10.3)), and were sufficiently sure that they could manage various diabetes-related situations in their day-to-day life (Mean = 7.3 (SD 1.8)). Further, the adolescent participants did not perceive a great deal of diabetes-related support from their friends (Mean = 4.3 (SD 4.1)) and perceived moderate levels of stress in their lives (Mean = 18.3 (SD 7.3)).

<table>
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<th>Table 3: Study Characteristics</th>
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<tr>
<td>Characteristic</td>
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<td><strong>Age (in years), Mean (SD); Range</strong></td>
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<tr>
<td><strong>Years with T1DM, Mean (SD); Range</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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</tr>
<tr>
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<tr>
<td><strong>Years at T1DM Camp, Mean (SD); Range</strong></td>
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Table 4: Study Variables – Descriptive Statistics

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<td>Collaborative Parental Involvement</td>
<td>291</td>
<td>49.4 (10.3)</td>
<td>12 – 60</td>
<td>12.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>291</td>
<td>7.3 (1.8)</td>
<td>1 – 10</td>
<td>1.50</td>
<td>10.0</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>291</td>
<td>18.3 (7.3)</td>
<td>0 – 40</td>
<td>0.0</td>
<td>37.0</td>
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<tr>
<td>DSSQ – Multiplicative (Frequency X Support)</td>
<td>291</td>
<td>4.3 (4.1)</td>
<td>-5 – 15</td>
<td>-0.6</td>
<td>15.0</td>
</tr>
<tr>
<td>Physical Functioning – QOL</td>
<td>291</td>
<td>87.4 (13.5)</td>
<td>25 – 100</td>
<td>28.1</td>
<td>100.0</td>
</tr>
<tr>
<td>Emotional Functioning – QOL</td>
<td>291</td>
<td>76.8 (19.7)</td>
<td>25 – 100</td>
<td>25.0</td>
<td>100.3</td>
</tr>
<tr>
<td>Social Functioning – QOL</td>
<td>291</td>
<td>87.5 (14.8)</td>
<td>25 – 100</td>
<td>30.0</td>
<td>100.1</td>
</tr>
<tr>
<td>School Functioning – QOL</td>
<td>291</td>
<td>75.7 (17.8)</td>
<td>25 – 100</td>
<td>25.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Total QOL Score</td>
<td>291</td>
<td>82.5 (12.2)</td>
<td>25 – 100</td>
<td>40.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Physical Health Summary Score – QOL</td>
<td>291</td>
<td>87.4 (13.5)</td>
<td>25 – 100</td>
<td>28.1</td>
<td>100.0</td>
</tr>
<tr>
<td>Psychosocial Health Summary Score – QOL</td>
<td>291</td>
<td>80.0 (13.8)</td>
<td>25 – 100</td>
<td>38.3</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Correlations between Study Variables

The correlation results between the study measures are depicted in Table 5. Perceived diabetes severity (i.e., “effect of diabetes”) was negatively correlated with physical, emotional, social and school functioning among adolescents with T1DM ($r = -0.233$ to $-0.152$, $p < 0.01$) and positively correlated with perceived stress ($r = 0.392$, $p < 0.01$). Collaborative parental involvement was positively correlated with school functioning among adolescents with T1DM ($r = 0.149$, $p < 0.05$) and negatively correlated with perceived stress ($r = -0.184$, $p < 0.01$). Higher scores for self-efficacy were associated with higher scores on each of the domains of the
Pediatric Quality of Life scale (r = 0.169 to 0.287, p < 0.01) and with lower scores on the perceived stress scale (r = -0.348, p < 0.01). Adolescents’ perceptions of friends’ support for diabetes care (DSSQ-Multiplicative) was positively correlated with collaborative parental involvement and self-efficacy (r = 0.320 and 0.223, p < 0.01, respectively). Lastly, perceived stress was negatively correlated with physical, emotional, social and school functioning quality of life domains among adolescents with T1DM (r = -0.436 to -0.274, p < 0.01).

**Table 5: Study Variables – Correlations**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Effect of Diabetes</td>
<td>1</td>
<td>-.040</td>
<td>-.116**</td>
<td>.392**</td>
<td>-.101</td>
<td>- .197**</td>
<td>-.233**</td>
<td>-.224**</td>
<td>-.152**</td>
</tr>
<tr>
<td>CPI</td>
<td>-.040</td>
<td>1</td>
<td>.415**</td>
<td>-.184**</td>
<td>.320**</td>
<td>.050</td>
<td>.109</td>
<td>.149*</td>
<td>.101</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>-.116**</td>
<td>.415**</td>
<td>1</td>
<td>-.348**</td>
<td>.223**</td>
<td>.172**</td>
<td>.169**</td>
<td>.287**</td>
<td>.204**</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>.392**</td>
<td>-.184**</td>
<td>-.348**</td>
<td>1</td>
<td>-.071</td>
<td>- .337**</td>
<td>-.436**</td>
<td>-.384**</td>
<td>-.274**</td>
</tr>
<tr>
<td>DSSQ – Multiplicative</td>
<td>-.101</td>
<td>.320**</td>
<td>.223**</td>
<td>-.071</td>
<td>1</td>
<td>-.014</td>
<td>.018</td>
<td>-.008</td>
<td>.011</td>
</tr>
</tbody>
</table>

N = 291

**Correlation is significant at the 0.01 level (2-tailed).**

**Correlation is significant at the 0.05 level (2-tailed).**

**Examination of Research Objectives**

**Objective 1:** Examine the impact of various factors (perceived stress, diabetes-specific parental involvement, self-efficacy for diabetes management, and perceived peer support) on adolescents’
self-reported HRQoL and assess the association between these factors and their self-reported HRQoL.

The two-step approach outlined by Anderson and Gerbing (1988) was utilized in order to test the proposed study model and examine the relationships hypothesized therein (See Figure 3). The first step tested the fit and construct validity of the measurement model.

**Fit and construct validity of the measurement model.** Measurement properties of the latent construct (HRQoL) were examined using Confirmatory Factor Analysis (CFA) (Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning served as indicators for the latent variable (HRQoL)). Maximum likelihood estimation was used for parameter estimation in the CFA. Model fit indices indicated good fit of the model with the study data (Chi-square [df] = 15.37 [2], p < 0.001; CFI = 0.95; RMSEA = 0.15). Based on the modification indices, improvements were made to the original measurement model by correlating the error terms for emotional (e2) and school functioning (e4). The fit of the final model improved marginally (Chi-square [df] = 6.43 [1], p = 0.01; CFI = 0.98; RMSEA = 0.14). Next the individual factor loadings were examined. The standardized loading estimates are depicted in Table 6. Each of the factor loadings in the model were > 0.5 and given that high loadings on a factor indicate that they all converge on some common point, the model can be considered to possess high convergent validity. Overall Cronbach’s alpha and that for each of the indicator variables of the latent variable HRQoL are depicted in Table 7. Excellent support for internal consistency was found in the study with all Cronbach’s alpha values being > 0.70.
<table>
<thead>
<tr>
<th>Parameter</th>
<th>Estimate</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>0.725</td>
<td>0.007</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>0.596</td>
<td>0.015</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>0.773</td>
<td>0.005</td>
</tr>
<tr>
<td>School Functioning</td>
<td>0.502</td>
<td>0.009</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Cronbach’s Alpha</th>
<th>No. of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>0.804</td>
<td>8</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>0.775</td>
<td>5</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>0.782</td>
<td>5</td>
</tr>
<tr>
<td>School Functioning</td>
<td>0.719</td>
<td>5</td>
</tr>
<tr>
<td>Overall</td>
<td>0.880</td>
<td>23</td>
</tr>
</tbody>
</table>

**Structural model and hypothesis testing.** Given that a satisfactory measurement model was obtained in the previous step, the next step was to examine the structural model. Maximum likelihood estimation (MLE) was utilized in order to test the structural model. Figure 3 depicts the modified Wallander and Varni’s model tested in this study. Model fit indices indicated poor fit of the modified model with the study data (Chi-square [df] = 98.20 [18], p < 0.001; CFI = 0.85; RMSEA = 0.12). Based on the modification indices, improvements were made to the original hypothesized study model. Causal paths between perceived diabetes severity and perceived stress and diabetes-related self-efficacy and perceived stress were included in the model. Model fit improved significantly compared to the original model (Chi-square [df] = 24.46
[16], \( p = 0.08 \); CFI = 0.98; RMSEA = 0.04) (Figure 4). The final model explained 49.1%, 40.4%, 59.1%, and 26.9% of the variance in physical, emotional, social and school functioning among adolescents with T1DM, respectively. The significant direct, indirect, and total effects of study variables on QOL are presented in Table 8.

Two variables, perceived diabetes severity and self-efficacy for diabetes management had a significant direct effect on perceived stress. Higher levels of perceived diabetes severity were associated with higher levels of perceived stress (standardized direct effect regression weight = 0.36, \( p < 0.05 \)).

**Figure 4. Final Structural Model**

Two variables, perceived diabetes severity and self-efficacy for diabetes management had a significant direct effect on perceived stress. Higher levels of perceived diabetes severity were associated with higher levels of perceived stress (standardized direct effect regression weight = 0.36, \( p < 0.05 \)).
Therefore,

$H_{new1}$: Adolescents’ perceived disease (i.e., T1DM) severity will be positively related to their perceived stress – Supported

Higher levels of self-efficacy for diabetes management were associated with lower levels of perceived stress (standardized direct effect regression weight = -0.29, p < 0.05).

Therefore,

$H_{new2}$: Adolescents’ self-efficacy for diabetes management will be negatively related to their perceptions of stress-- Supported

Higher levels of perceived diabetes severity were associated with poorer QOL (standardized direct effect regression weight = -0.13, p = 0.056).

Therefore,

$H_1$: Adolescents’ perceived disease (i.e., T1DM) severity will be negatively related to their self-reported HRQoL – Supported

Higher levels of perceived stress were also associated with poorer QOL (standardized direct effect regression weight = -0.43, p < 0.05).

Therefore,
**H2: Adolescents’ perceived stress regarding having T1DM will be negatively related to their self-reported HRQoL – Supported**

Higher levels of self-efficacy for diabetes management were associated with better QOL (standardized direct effect regression weight = 0.16, \( p < 0.05 \)).

Therefore,

**H7: Adolescents’ self-efficacy for diabetes management will be positively related to their self-reported HRQoL -- Supported**

Higher levels of collaborative parental involvement were associated with lower levels of perceived stress and better QOL, albeit both these relationships were non-significant.

**H3: Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be positively related to adolescents’ self-reported HRQoL – Not supported**

**H4: Adolescents’ perceived diabetes-specific (collaborative) parental involvement will be negatively related to their perceptions of stress – Not supported**

| Table 8: Structural Model – Standardized Total, Direct and Indirect Effects |
|---------------------------|-----------------|-----------------|-----------------|
| Parameter | Total Effect | Direct Effect | Indirect Effect |
| Perceived Stress | ---<---- | CPI | -0.066 | -0.066 | - |
| Perceived Stress | ---<---- | DSSQ – Multiplicative | 0.051 | 0.051 | - |
| Perceived Stress | ---<---- | Effect of Diabetes | 0.361* | 0.361* | - |
| Perceived Stress | ---<---- | Self-Efficacy | -0.290* | -0.290* | - |
| Quality of life | ---<---- | Effect of Diabetes | -0.279* | -0.125 | -0.154* |
| Quality of life | ---<---- | Self-Efficacy | 0.286* | 0.163* | 0.124* |
| Quality of life | ---<---- | Perceived Stress | -0.427* | -0.427* | - |
| Quality of life | ---<---- | CPI | 0.062 | 0.034 | 0.028 |
| Quality of life | ---<---- | DSSQ – Multiplicative | -0.115* | -0.093 | -0.022 |

* Significant at the 0.05 level (2-tailed)
Mediation Analyses

Several mediating effects were hypothesized in the original model and two additional paths were suggested from the diagnostics of the original model (Figure 3) – (1) a direct path from self-efficacy to perceived stress and (2) a direct path from effect of diabetes to perceived stress. When these direct relationships were included model fit was dramatically improved. This next analysis tested whether the new path estimates were significant in addition to improving model fit. It also tested the originally hypothesized mediating effects. Perceived stress was found to mediate the relationship between effect of diabetes and quality of life (full mediation) and between self-efficacy and quality of life (partial mediation) (See Table 9). Further, the originally hypothesized mediating effects (CPI – Perceived Stress – Quality of Life and DSSQ-Multiplicative – Perceived Stress – Quality of Life) were found to be insignificant.

<table>
<thead>
<tr>
<th>Table 9: Structural Model – Mediation Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
</tr>
<tr>
<td>---------------</td>
</tr>
<tr>
<td>Effect of Diabetes – Perceived Stress – Quality of Life</td>
</tr>
<tr>
<td>Self-Efficacy – Perceived Stress – Quality of Life</td>
</tr>
<tr>
<td>CPI – Perceived Stress – Quality of Life</td>
</tr>
<tr>
<td>DSSQ-Multiplicative – Perceived Stress – Quality of Life</td>
</tr>
</tbody>
</table>

* Significant at the 0.05 level (2-tailed)
**Objective 2:** Determine if differences in perceptions exist between diabetes camp and non-camp adolescent attendees on their perceived level of stress, perceived disease severity, perceived parental involvement and peer support, ability to manage their condition and their HRQoL.

Since the data are non-normal, the non-parametric Mann-Whitney U Test was utilized (in place of the originally proposed Independent samples t-test) to compare various scale scores obtained from the adolescents attending a diabetes summer camp with those obtained from adolescents that have never attended a diabetes summer camp (Responses collected from either the university or community-based diabetes clinics).

Results from the Mann-Whitney U Test are depicted in Table 10. No significant differences in scale scores were found across the two groups for all but two study variables -- CPI and DSSQ-Multiplicative (p < 0.05). A caveat to the Mann-Whitney U test is that it assumes the variances of the two groups being measured to be equal. On examining the results of the Levene’s Test of Equality of Variances it was gleaned that the test was statistically significant for CPI and DSSQ-Multiplicative (See Table 11), therefore indicating unequal variances across the two groups for these variables. Unequal variances can affect the Type I error rate and therefore these results need to be interpreted with caution.
## Table 10: Mann-Whitney U Test

<table>
<thead>
<tr>
<th></th>
<th>Camp/ Clinic</th>
<th>N</th>
<th>Mean Rank</th>
<th>Mann-Whitney U</th>
<th>Sig.</th>
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<tbody>
<tr>
<td><strong>Effect of Diabetes</strong></td>
<td>Camp</td>
<td>237</td>
<td>141.9</td>
<td>5426.5</td>
<td>0.079</td>
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<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>164.0</td>
<td></td>
<td></td>
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<tr>
<td><strong>Collaborative Parental Involvement</strong></td>
<td>Camp</td>
<td>237</td>
<td>136.2</td>
<td>4072.5</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>189.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-Efficacy</strong></td>
<td>Camp</td>
<td>237</td>
<td>141.9</td>
<td>5435.0</td>
<td>0.084</td>
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<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>163.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived Stress</strong></td>
<td>Camp</td>
<td>237</td>
<td>144.6</td>
<td>6070.0</td>
<td>0.555</td>
</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>152.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DSSQ – Multiplicative (Frequency X Support)</strong></td>
<td>Camp</td>
<td>237</td>
<td>144.1</td>
<td>5105.0</td>
<td>0.020</td>
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<td></td>
<td>Clinic</td>
<td>54</td>
<td>154.3</td>
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<tr>
<td><strong>Physical Functioning – QOL</strong></td>
<td>Camp</td>
<td>237</td>
<td>149.3</td>
<td>5950.0</td>
<td>0.414</td>
</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>131.7</td>
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<tr>
<td><strong>Emotional Functioning – QOL</strong></td>
<td>Camp</td>
<td>237</td>
<td>147.8</td>
<td>5625.5</td>
<td>0.162</td>
</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>138.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Functioning – QOL</strong></td>
<td>Camp</td>
<td>237</td>
<td>149.6</td>
<td>5984.5</td>
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</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>130.4</td>
<td></td>
<td></td>
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<tr>
<td><strong>School Functioning – QOL</strong></td>
<td>Camp</td>
<td>237</td>
<td>147.6</td>
<td>5557.5</td>
<td>0.130</td>
</tr>
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<td></td>
<td>Clinic</td>
<td>54</td>
<td>139.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total QOL Score</strong></td>
<td>Camp</td>
<td>237</td>
<td>140.5</td>
<td>6021.5</td>
<td>0.499</td>
</tr>
<tr>
<td></td>
<td>Clinic</td>
<td>54</td>
<td>170.0</td>
<td></td>
<td></td>
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</table>

## Table 11: Test of Homogeneity of Variances

<table>
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<tr>
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<th>df1</th>
<th>df2</th>
<th>Sig.</th>
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<tbody>
<tr>
<td><strong>Effect of Diabetes</strong></td>
<td>0.000</td>
<td>1</td>
<td>289</td>
<td>1.000</td>
</tr>
<tr>
<td><strong>Collaborative Parental Involvement</strong></td>
<td>7.042</td>
<td>1</td>
<td>289</td>
<td><strong>0.008</strong></td>
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<tr>
<td><strong>Self-Efficacy</strong></td>
<td>0.208</td>
<td>1</td>
<td>289</td>
<td>0.649</td>
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<tr>
<td><strong>Perceived Stress</strong></td>
<td>0.011</td>
<td>1</td>
<td>289</td>
<td>0.916</td>
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<tr>
<td><strong>DSSQ – Multiplicative (Frequency X Support)</strong></td>
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<td>1</td>
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<td><strong>0.003</strong></td>
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<tr>
<td><strong>Physical Functioning – QOL</strong></td>
<td>0.240</td>
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<tr>
<td><strong>Social Functioning – QOL</strong></td>
<td>0.609</td>
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<td>289</td>
<td>0.436</td>
</tr>
<tr>
<td><strong>School Functioning – QOL</strong></td>
<td>1.271</td>
<td>1</td>
<td>289</td>
<td>0.260</td>
</tr>
<tr>
<td><strong>Total QOL Score</strong></td>
<td>0.021</td>
<td>1</td>
<td>289</td>
<td>0.885</td>
</tr>
</tbody>
</table>
Multi-group SEM Analyses

This analysis focused on similarities and differences between structural parameters to identify differences in relationships between the groups (adolescents attending a diabetes summer camp compared with those who have never attended a diabetes summer camp (Responses collected from either the university or community-based diabetes clinics)). A chi-square difference test was performed comparing the unconstrained and constrained models. The result was found to be consistent with invariant structural parameter estimates, and thus inconsistent with the prediction that the relationships specified in the model would be different across the two groups. In spite of this previous finding that the groups were not different at the model level, a path by path analysis was performed to assess if any of the individual paths (perceived level of stress to HRQoL, perceived disease severity to HRQoL, perceived parental involvement to HRQoL, peer support to HRQoL, ability to manage their T1DM to HRQoL) were moderated by the grouping/moderating variable (i.e., T1DM Camp/T1DM Clinic). Again, the grouping variable did not significantly moderate the relationship between any of the study variables (perceived level of stress, perceived disease severity, perceived parental involvement and peer support, ability to manage their T1DM) and HRQoL (See Table 12) (Note: Analysis run using macro in MS Excel (Gaskin J, 2011)).
<table>
<thead>
<tr>
<th>Relationship</th>
<th>Camp</th>
<th></th>
<th>Clinic</th>
<th></th>
<th>z-score</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate</td>
<td>Sig.</td>
<td>Estimate</td>
<td>Sig.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>&lt;--- CPI</td>
<td>-0.034</td>
<td>0.428</td>
<td>-0.236</td>
<td>0.113</td>
<td>-1.305</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>&lt;--- DSSQ-Multiplicative</td>
<td>0.090</td>
<td>0.416</td>
<td>0.028</td>
<td>0.900</td>
<td>-0.245</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>&lt;--- Effect of Diabetes</td>
<td>1.085</td>
<td>0.000</td>
<td>1.168</td>
<td>0.003</td>
<td>0.190</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>&lt;--- Self-Efficacy</td>
<td>-1.242</td>
<td>0.000</td>
<td>-0.561</td>
<td>0.369</td>
<td>1.011</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>&lt;--- Effect of Diabetes</td>
<td>-0.348</td>
<td>0.230</td>
<td>-1.088</td>
<td>0.090</td>
<td>-1.051</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>&lt;--- Self-Efficacy</td>
<td>0.889</td>
<td>0.033</td>
<td>0.655</td>
<td>0.478</td>
<td>-0.231</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>&lt;--- Perceived Stress</td>
<td>-0.608</td>
<td>0.000</td>
<td>-0.475</td>
<td>0.023</td>
<td>0.564</td>
</tr>
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<td>&lt;--- CPI</td>
<td>0.029</td>
<td>0.662</td>
<td>0.076</td>
<td>0.733</td>
<td>0.200</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>&lt;--- DSSQ-Multiplicative</td>
<td>-0.176</td>
<td>0.308</td>
<td>-0.333</td>
<td>0.315</td>
<td>-0.420</td>
</tr>
</tbody>
</table>

* Significant at the 0.05 level (2-tailed) – No significant relationships detected
CHAPTER V

DISCUSSION AND IMPLICATIONS

Wallander and Varni’s Risk and Resistance Model was utilized as a guiding framework for this study (Wallander & Varni, 1998). HRQoL serves as an important comprehensive indicator of the health condition of a particular person and thus, the study model included HRQoL as a measure of psychosocial adjustment/adaptation in children with T1DM. Consistent with the Risk and Resistance Model, in this study the influence of disease severity, psychosocial stress (e.g., perceived stress), personal factors (e.g., self-efficacy for diabetes management) and social ecological factors (e.g., parental involvement and peer support) were assessed on a child’s psychosocial adaptation to his/her disease (i.e., T1DM). The study model also assessed whether the aforementioned social ecological factors indirectly influenced psychosocial adaptation through psychosocial stress.

An SEM approach was utilized in this study to test the proposed study model and determine the degree to which it is consistent with the data. Additionally, SEM allowed specification and testing of both direct and indirect paths between variables within the proposed model. Such complex paths are difficult to model using standard multiple regression techniques. Furthermore, the SEM approach allowed for the incorporation of both observed and unobserved (i.e., latent) variables with multiple indicators. Standard regression techniques would not have
permitted the inclusion of multiple indicators (Byrne, 2001). Thus, in this study it was possible to incorporate HRQoL as a latent construct with multiple indicators. The results from this study indicated that the proposed model had a good fit and was therefore consistent with the data.

The various aforementioned illness perceptions that were examined in this study explained 49.1%, 40.4%, 59.1%, and 26.9% of the variance in physical, emotional, social and school functioning (i.e., quality of life domains) among adolescents with T1DM, respectively. To the best of our knowledge, this is the first study to assess the impact of adolescents’ illness perceptions on HRQoL. The self-reported questionnaire format that was utilized makes the results of this study more pertinent as they represent the adolescents’ personal outlook on the impact of their condition on their day to day life. Results from this study can be utilized in order to develop interventions to improve illness-related perceptions and subsequently HRQoL among adolescents with T1DM. By identifying predictors of illness perceptions, interventions can focus on those factors that can be easily modified so as to improve adolescents’ psychosocial adaptation to T1DM.

**Risk Factors**

**Perceived Disease Severity.** Perceived diabetes severity was assessed in this study by asking respondents to indicate the effect or impact their diabetes had on their daily lives\(^5\). Thus, this measure provided an account of the responding adolescents’ subjective assessment of their disease severity. This is in contrast to how disease severity is frequently assessed in studies as a function of glycemic control or various symptoms (e.g., hypoglycemia, nephropathy, neuropathy, neuropathy,

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\(^5\) Refer to Effect of Diabetes (Measure 10) on pp. 38
etc.) that manifest after the onset of T1DM (Hoey et al., 2001; Hassan et al., 2006; Lawrence et al., 2012; Wagner et al., 2005).

In the present study, perceived diabetes severity was found to be negatively correlated with total quality of life as well as with the individual domains of quality of life including, physical, emotional, school and social functioning (p < 0.01). As hypothesized, higher levels of perceived diabetes severity were found to be associated with poorer quality of life (p = 0.056) when examining individual relationships in the SEM model. Higher levels of perceived diabetes severity were also found to be associated with higher levels of perceived stress (p < 0.05) in the model. Further, in this study, perceived stress was found to fully mediate the relationship between perceived diabetes severity and quality of life. These findings are in line with previous work detailing the association between both glycemic control and quality of life and glycemic control and stress (Hoey et al., 2001; Hassan et al., 2006; Lawrence et al., 2012; Wagner et al., 2005; Hains et al., 2006; Lloyd et al., 1999; Wiesli et al., 2007).

To the best of our knowledge, this is the first study to document the association of ‘perceived disease severity’ with quality of life and stress in an adolescent population with T1DM. Perceptions of disease severity are important to capture at an individual level, as adolescents may interpret the severity of their condition in different ways and to different extents, possibly depending on factors such as the duration of their T1DM, their age, their level of understanding of T1DM, etc. For example, an adolescent who has been managing his/her condition for a longer duration may not perceive his/her diabetes to be as severe, as compared to one who has been (more) recently diagnosed with the condition which in turn will have an impact on the adolescent’s quality of life and the amount of stress they perceive. Adolescents may also perceive their diabetes to be severe if they have to frequently correct abnormally high
(hyperglycemia) or low (hypoglycemia) blood glucose levels, once again having an impact on their perceptions of stress and quality of life.

Reducing concerns related to diabetes severity might lead to reduced amount of stress and possibly better psychosocial adjustment to the disorder (i.e., better quality of life). Providing adolescents with easy to digest information regarding diabetes in general, diabetes-related symptoms, glycemic control, etc. and providing opportunities for adolescents to talk to those who have expertise related to diabetes so that they can receive specific information about disease severity and how diabetes might affect their future may help alleviate concerns and improve perceptions related to disease severity in this group.

**Perceived Stress.** General stress perceived by adolescents with T1DM (i.e., situations which were deemed as unpredictable, uncontrollable, and overloaded) and its impact on their quality of life was assessed in this study. Perceived stress was found to be negatively correlated with all aspects of quality of life, including, physical, emotional, social and school functioning among adolescents with T1DM ($p < 0.01$). Further, as hypothesized in the study model, higher levels of perceived stress were associated with poorer quality of life ($p < 0.05$).

These effects of general stress on quality of life could be explained by several factors, including emotional trauma of the diagnosis of a life-long/life-threatening condition, burdens related to the management of the disease, and other disease-related fears and concerns. They could also be explained by non-disease-related factors such as puberty, changes in school as well as shifts in family, peer, and/or romantic relationships. Thus, coping with the physical, emotional as well as social demands of self-management of T1DM during adolescence can be a rather
Challenging task. While perhaps not a standard practice today, there may be room for coping skills training (CST) to aid adolescents with T1DM in navigating these challenges.

Coping skills training (CST) is based on the premise that practicing and rehearsing a new behavior, such as learning to cope successfully with a problematic or stressful situation can result in better outcomes and promote positive behaviors (Grey et al., 2000). The goal of this coping intervention is thus to retrain non-constructive coping styles and behaviors into more constructive behaviors. Specific coping skills that can be addressed among adolescents with T1DM that perceive a great deal of stress in their lives include but are not limited to recognition of associations between thoughts, feelings, and behavior and guided self-dialogue, emotional expression, acceptance, and teaching of stress management techniques such as deep breathing, muscle relaxation, and guided imagery (Grey et al., 2009; Jaser and White, 2011).

Results from this study are consistent with previous reports that have demonstrated a negative relationship between both physiological and psychosocial adjustment and perceived stress (Hanson and Pichert, 1986; Grey et al., 2000; Jaser and White, 2011). However, this is the first study to the best of our knowledge to have directly assessed the impact of perceived stress on quality of life of adolescents with T1DM. Future studies can evaluate both diabetes-specific stress and general stress to appreciate if this relationship with quality of life persists. Further, these studies should assess which type of stress has a larger impact on quality of life (if any) so as to be able to tailor coping interventions for adolescents with T1DM accordingly and effectively.
Resistance Factors

Self-efficacy for Diabetes Management. Adolescents’ perceptions regarding their ability to manage their diabetes and associated problematic situations that may arise on a day-to-day basis were assessed in this study. Self-efficacy was conceptualized as the adolescent’s confidence in his or her ability to handle situations related to his/her T1DM. A number of studies in the literature have previously documented the relationship between self-efficacy and metabolic control and a few studies have documented the relationship between self-efficacy and quality of life as well among adolescents with T1DM (Griva et al., 2000; Iannotti et al., 2006; Johnston-Brooks, Lewis, & Garg, 2002; Ott et al., 2000; Grey et al., 2000). Although these relationships have been documented in the past, there was incomplete understanding of the impact of self-efficacy on relevant outcome measures such as quality of life. The findings from this study, i.e., higher levels of self-efficacy for diabetes management were associated with lower levels of perceived stress and better quality of life (p < 0.05), were found to be in agreement with the aforementioned extant literature on this subject and contribute to the filling of this gap in current knowledge on this subject.

Furthermore, self-efficacy for diabetes management was included as a factor in the study model, as it is an integral aspect of the lives of adolescents with T1DM. Significant effort and commitment is required on the part of the adolescent based on current standards related to the management of diabetes. How adolescents cope with the stress of a chronic condition such as T1DM has a tremendous impact on their adaptation to the illness. The acquisition of complex health behaviors that are necessary in the self-management of T1DM requires adolescents to have strong self-efficacy beliefs (Whittemore et al., 2010). This study had similar findings, wherein perceived stress was found to mediate the relationship between self-efficacy and quality
of life (partial mediation). As discussed before, interventions such as coping skills training can possibly facilitate adolescents’ ability to cope with diabetes-related stressors that they face on a daily basis and help them achieve their therapeutic and general outcome goals. Additionally, it is believed that such interventions will not only help adolescents adapt to their condition but will also generalize to other day-to-day life experiences and therefore influence and improve self-efficacy (Grey et al., 2000).

**Perceived Diabetes-specific Parental Involvement.** Given that as a group adolescents display the worst glycemic control compared with other age groups, sustained levels of parental support during this time – collaborative versus authoritarian in nature – is necessary for optimal diabetes management and psychosocial outcomes (de Wit et al., 2008; Anderson et al., 1997; Berg et al., 2008; Wiebe et al., 2005; Weissberg-Benchell et al., 2009). In this study, perceived collaborative parental involvement was found to be positively correlated with school functioning (p < 0.05) and negatively correlated with perceived stress (p < 0.01) among adolescents with T1DM. As hypothesized, higher levels of collaborative parental involvement were associated with lower levels of perceived stress and better quality of life among adolescents with T1DM when examining individual relationships in the SEM model.

Although the results from this study were consistent with reports that documented these aforementioned relationships in the past, in this study both these relationships were found to be non-significant. One possible reason for this could be that even though on average the adolescents with T1DM in this sample perceived a significant amount of collaborative involvement by their parent(s) in managing their diabetes (mean = 49.4 with maximum allowable score on this scale being 60), the variation was large (SD = 10.3) and thus, resulted in a weak effect. It is possible that this effect may strengthen when measured over a longer period of time,
i.e., continuing parental support and guidance may help adolescents significantly reduce their stress and improve their quality of life. Further, it is also possible that some adolescents may perceive parental support (even though collaborative in nature) negatively. Adolescents, especially teenagers, may want increasing amounts of control over their daily activities, including the management of their diabetes and may thus perceive parental involvement as an inhibitor to successfully managing their life and diabetes independently.

Adaptive family functioning and regularity of family functioning can both serve as protective mechanisms among children who are managing chronic conditions such as T1DM (Drotar, 1997; Austin et al., 2006). Routines that provide for regularity of family activities along with communication surrounding who is responsible for managing a particular task/activity on a regular basis might be protective by providing structure for adolescents dealing with unpredictable diabetes-related situations that may arise, sometimes even on a daily basis (Markson and Fiese, 2000; Austin et al., 2006). Psychosocial interventions that can facilitate or improve communication among adolescents with T1DM and their families can help the family as a whole navigate, manage and adapt to this complex, chronic illness. Further, interventions that can help adolescents and their parents negotiate the balance between adolescent self-care and maintenance of parental guidance in the management of this condition, may help with achieving better physiological as well as psychosocial outcomes among adolescents with T1DM (Grey et al., 2001). However, this may be a difficult balance to achieve and may possibly depend on the personalities of the adolescent and the parent(s) involved.

**Perceived Diabetes-specific Peer Support.** During adolescence, peers tend to make an increasing impact in terms of presence and thus adolescents tend to rely more on similar-aged individuals/friends in order to ascertain behavioral norms (Wysocki & Greco, 2006).
Additionally, peers also tend to be an important source of social support (Berndt, 1992). Among adolescents with T1DM, although some studies have found peer support to be related to improved health-related outcomes, the research is equivocal and others have not found these associations. In this present study, no significant association was documented between perceived diabetes-specific peer support and both perceived stress or quality of life, when examining individual relationships in the SEM model. Furthermore, these relationships were found to be in a direction opposite to what was initially hypothesized, i.e., perceived diabetes-specific peer support was found to be negatively related to quality of life and positively related to perceived stress among adolescents with T1DM, the caveat being that these effects were very weak at best.

These results are not out of the ordinary and similar findings have been reported in the past. Adolescents tend to find adhering to their diabetes regimens increasingly difficult when their peers have negative reactions toward the management of their condition. Furthermore, support provided by peers can also be maladaptive in nature, which leads to adolescents (with T1DM) making poor diabetes-related behavioral decisions (Hains et al., 2007). Adolescents also tend to find it challenging to balance social expectations with their own personal needs which in turn may result in poor health outcomes (Peters, Nawijn & Kesteren, 2014). One possible methodological reason for these results is that the scale utilized to assess perceived diabetes-related peer support in this study was not understood well by the responding adolescents (at diabetes camps and clinics). They reported the scale as being confusing and lengthy, which may have been the reason why many respondents left large sections of the scale incomplete or utilized straight-lining as a response strategy for this scale (these responses were not included in the final sample). Future studies should assess this relationship using a more concise scale that captures peer-related experiences of adolescents with T1DM.
Interventions that involve social problem solving skills and conflict resolution skills training can help train adolescents with T1DM to develop new, less differentiating behaviors that allow them to adhere to their intensive diabetes regimes without compromising peer relationships. Social skills training can help adolescents communicate more openly with their peers regarding their diabetes and topics surrounding their condition. Important topics of communication that can be addressed include openly revealing their diagnosis to peers, being more comfortable managing difficult situations such as food choices, decision making regarding alcohol, etc.

**Diabetes-specific Camps versus Diabetes Clinics**

No significant differences in the various adolescent illness perceptions that were assessed in this study or the impact of these illness perceptions on perceived stress and quality of life were found among adolescents with T1DM who frequent diabetes camps versus those who don’t (our diabetes clinic population). These findings were contrary to what was expected given that diabetes-specific camps can and do provide an appropriate environment for adolescents with chronic diseases like T1DM to learn positive coping skills and strategies among supportive peers. Diabetes-camps provide experiences that can facilitate a deeper understanding of the condition among adolescents with T1DM, help them recognize their true potential in spite of their condition, help foster a healthy and positive attitude toward their condition, and foster lasting friendships (Timmons, 2009).

There are a few potential reasons for these contradictory findings. One possible reason is that there was a large difference between the sample sizes of the two groups (respondents from camp = 237; respondents from clinics who had never partaken in a diabetes camp = 54); the
other being that majority of the sample from the diabetes clinics (n = 51) was from one single clinic in a southern U.S. state. Another reason why there were no differences among groups could be that those adolescents that self-select camps are predisposed to benefit as they recognize a need in themselves for social exploration of their illness in a safe environment whereas those who don’t probably don’t need it. Lastly, adolescents in this sample had attended a diabetes camp for approximately 3 years (with an SD of 2.5 years). Given this large variation, it is possible that adolescents in this sample had not attended diabetes camps for a long enough period to have fully benefited from them and thus their illness perceptions were not significantly different from those who had not. These reasons together could have resulted in skewing the data.

Given the non-significant results garnered for this relationship in the study, limited understanding still exists regarding the differences in perceptions of adolescents with T1DM who frequent diabetes camps versus those who don’t on various psychosocial factors that impact their condition as well as their life in general. Future studies should attempt to collect data from multiple clinics across different geographic locations (large sample size of non-camp going respondents) to circumvent the issues experienced in this study. Further, in order to assess the beneficial effect of a diabetes camp on quality of life and other diabetes-related perceptions, future studies could assess the impact of number of years having attended a diabetes camp on various health-related outcomes.
Limitations

As with any study, there are a number of limitations present in this study. First, the sample of respondents that participated in the study are not representative of all adolescents with T1DM. Additionally, responses obtained from those adolescents that regularly attend a diabetes summer camp may not be typical of all adolescents with T1DM, restricting the generalizability of the findings from this study. Since our sample consists of adolescents between 11 and 16 years of age, there may be issues related to flippancy and boredom and the participants may not have been motivated to complete the survey, especially given that majority of the participants were at a summer camp. These issues may have potentially had an impact on the quality of the data that was collected throughout this study.

A cross-sectional design was utilized in this study. This precludes the research team from offering any information about causal relationships among the different variables included in the study. Only a longitudinal study can explicate the direction of the relationships among the variables being studied. Longitudinal assessments may help the researchers determine the extent to which changes in adolescents’ illness attitudes over time relate to changes in HRQoL. Furthermore, prospective longitudinal investigations of adolescents with T1DM may be quite informative as such studies will provide researchers an opportunity to examine change during critical developmental periods in adolescence (Whittemore et al., 2010). Lastly, no measure of adolescents’ personalities was included in this study. Including such a measure in future studies may allow clustering of adolescents by personality type and thus enable better understanding of the results.
Conclusion

Given that an adolescent’s feelings about his/her illness may significantly impact how the he/she copes with and ultimately adapts to the chronic illness (Austin & Huberty, 1993; Austin, Patterson, & Huberty, 1991), it is important to capture various illness perceptions among adolescents with T1DM. This research addresses an important gap in the literature by clarifying the impact of various social-behavioral factors, which are amenable to intervention, on the quality of life of adolescents with T1DM. The findings from this study will enable the delivery of more directed patient-centered care by providing insight to help improve the quality of the lives of young people living with T1DM. This research opens a window of observation in an area that has not been widely researched before -- social behavioral influences on comprehensive care for youth with T1DM, an underrepresented population. Furthermore, this research makes valuable contributions to social-behavioral theory in pharmacy practice, and possibly even to other disciplines such as medicine and nursing and can potentially guide researchers and health care providers in their thinking about adaptation to T1DM among adolescents.

The multitude of factors that influence adaptation to T1DM during childhood and adolescence suggest the need for comprehensive ongoing assessment and multidisciplinary care, particularly at various developmental transitions. Multidisciplinary care can be beneficial in that it can meet the needs and preferences of various patient and parent personalities as well as provide flexible access to advice from various health professionals. In order for multidisciplinary care to have a potential impact on the lives of adolescents with T1DM it is important for health care providers and other professionals of the collaborative team to ensure that they provide consistent advice; maintain similar service standards; make every effort to build a therapeutic relationship with the patient; and provide opportunities for joint consultations with the
multidisciplinary team clinicians. Thus, it is anticipated that findings from this study will help increase knowledge regarding the care and management of young people with T1DM and will likely stimulate dialog and additional research among an inter-professional and interdisciplinary community of scholars, including pediatric endocrinologists, nurses, certified diabetes educators, dietitians and nutritionists, camp directors and counselors, psychologists, etc.
BIBLIOGRAPHY


LIST OF APPENDICES
APPENDIX A: Survey Instrument
SURVEY

GENERAL INSTRUCTIONS:

Thank you for agreeing to take part in this study. This survey will take no more than 15 minutes to complete. Please make sure you answer ALL the questions as honestly and accurately as you can. If you need help at any time when filling out the booklet, feel free to talk to the researcher.

This information will not be shared with your doctor or your parent(s). This information is being collected only to understand what individuals like you think about your diabetes and to help health care workers take better care of you.

SECTION I:

Please answer the following questions about yourself and your condition.

1. What is your age? __________________________

2. What is your gender?
   - Male
   - Female

3. What is your race?
   - White/Caucasian
   - Black/African American
   - Other
   - Not sure

4. What is your ethnicity?
   - Hispanic/Latino
   - Not Hispanic/Latino
   - Not sure

5. For how many years have you had diabetes? __________________________
6. Have you ever attended a diabetes summer camp?
   ○ Yes
   ○ No

7. For how many years have you attended a diabetes summer camp? ________________

8. What type of insulin therapy do you use?
   ○ Injections
   ○ Insulin pump

9. How many times in a day do you check your blood glucose levels? ________________

10. On a scale of 1 to 10, how much does your diabetes affect you (where, 1 = Not at all and 10 = A great deal)?
    (Circle the number that shows how much your diabetes affects you)

   1  2  3  4  5  6  7  8  9  10

11. Do you feel your diabetes is under control?
    ○ Yes
    ○ No
    ○ Not sure
SECTION II:

Collaborative Parent Involvement Scale (CPI)

Directions: In each case, circle the number that indicates your parents involvement with various tasks related to your diabetes care.

I have a parent who . . .

<table>
<thead>
<tr>
<th></th>
<th>1 = Almost never</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 = Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps me plan my diabetes care to fit my schedule.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Knows when I need a little extra help with my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me figure out how to change my insulin or eating to fit the amount I exercise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me out when I am too tired or stressed to take care of my diabetes on my own.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me learn how to take care of troubles I have with my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me plan how to spend time with my friends and still take good care of my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Talks with me about how to adjust (change) my insulin, eating, and exercise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me with my diabetes when I need it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Helps me take care of any problems I am having at school with taking care of my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Knows what things are hard for me in taking care of my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Knows when to let me do more to take care of myself and my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Knows how I am taking care of my diabetes when I am with friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**Self-efficacy for Diabetes Self-management (SEDM)**

**Directions:** Living with diabetes can sometimes be difficult. Listed below are a variety of situations you may face in day-to-day life.

**How sure are you that you can do each of the following, almost all the time?** (Circle the number that indicates this for each situation listed below).

<table>
<thead>
<tr>
<th></th>
<th>1 = Not sure at all</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 = Completely sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjust your insulin correctly when you eat more or less than usual.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Choose healthful foods when you go out to eat.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Exercise even when you don't really feel like it.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Adjust your insulin or food accurately based on how much</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Talk to your doctor or nurse about any problems you're having with taking care of your diabetes.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Do your blood sugar checks even when you are really busy.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Manage your diabetes the way your health care team wants you</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Manage your diabetes even when you feel overwhelmed.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Find ways to deal with feeling frustrated about your diabetes.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Identify things that could get in the way of managing your diabetes.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
Perceived Stress Scale (PSS)

**Directions:** The following questions ask you about your feelings and thoughts **during the last month**. In each case, circle the number that indicates how often you felt or thought a certain way.

**In the last month …**

<table>
<thead>
<tr>
<th>Question</th>
<th>0 = Never</th>
<th>1 = Almost Never</th>
<th>2 = Sometimes</th>
<th>3 = Fairly often</th>
<th>4 = Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often have you been upset because of something that happened unexpectedly?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt that you were unable to control the important things in your life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt nervous and “stressed”?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt confident about your ability to handle your personal problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt that things were going your way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you found that you could not cope with all the things that you had to do?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you been able to control irritations in your life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt that you were on top of things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you been angered because of things that were outside of your control?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often have you felt difficulties were piling up so high that you could not overcome them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DSSQ: FRIENDS

We want to know how often your friends do things to help or support your diabetes. There are no right or wrong answers. Just circle the number that indicates how often these things happen with your friends.

We also want to know how you feel about your friends’ behaviors. Everyone has different ideas about what is helpful and supportive. We want to know what is helpful and supportive for you. Circle the number that shows how supportive each behavior is for YOU.

These are the scales to use in answering the questions:

<table>
<thead>
<tr>
<th>How Often Do Your Friends.....</th>
<th>When this happens, how do you feel about it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = Never</td>
<td>-1 = Unhelpful or NOT supportive</td>
</tr>
<tr>
<td>1 = Less than 2 times a month</td>
<td>0 = Neutral</td>
</tr>
<tr>
<td>2 = Twice a month</td>
<td>1 = A little helpful or supportive</td>
</tr>
<tr>
<td>3 = Once a week</td>
<td>2 = Helpful/ Supportive</td>
</tr>
<tr>
<td>4 = Several times a week</td>
<td>3 = Very supportive</td>
</tr>
<tr>
<td>5 = At least once a day</td>
<td></td>
</tr>
</tbody>
</table>

Note: If a behavior listed never happens, circle “0” for “never”. Please try to rate how you think you would feel if this did happen.
<table>
<thead>
<tr>
<th>INSULIN SHOTS</th>
<th>When this happens, how do you feel about it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remind you to take your insulin</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
<tr>
<td>Let you know they appreciate how difficult it is to take insulin injections.</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BLOOD TESTING</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask you about the results of your blood tests.</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
<tr>
<td>Watch you test your blood sugars to see what the values are.</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
<tr>
<td>Remind you to test your blood sugar.</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
<tr>
<td>Let you know that they appreciate how hard it is to test blood sugars every day.</td>
<td>-1  0  1  2  3  4  5</td>
</tr>
<tr>
<td><strong>BLOOD TESTING</strong></td>
<td><strong>When this happens, how do you feel about it?</strong></td>
</tr>
<tr>
<td>------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Watch you for signs that your blood sugar is low.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Help out when you might be having a reaction.</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>MEAL PLAN</strong></th>
<th><strong>When this happens, how do you feel about it?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Encourage you to eat the right foods.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Let you know they understand how important it is for you to eat right.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Ask if certain foods are okay for you to eat, before serving them.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Schedule meals at the times you need to eat.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Remind you about sticking to your meal plan.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>How Often Do Your Friends.....</td>
<td>When this happens, how do you feel about it?</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td><strong>MEAL PLAN</strong></td>
<td></td>
</tr>
<tr>
<td>Suggest foods you can eat on your meal plan.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Join you in eating the same foods as you.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Get on your case after you ate something you shouldn't.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Avoid tempting you with food or drinks that you shouldn't have.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Watch what you eat to make sure that you eat the right foods.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Eat at the same time you do.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Buy special foods that you can eat.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Tell you not to eat something you shouldn't.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>EXERCISE</td>
<td>How Often Do Your Friends.....</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Suggest ways you can get exercise.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Invite you to join exercising with them.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Encourage you to join an organized sports activity (e.g., little league, gymnastics).</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Exercise with you.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>GENERAL</td>
<td></td>
</tr>
<tr>
<td>Are available to listen to concerns or worries about your diabetes care.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Encourage you to do a good job of taking care of your diabetes.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Understand when you sometimes make mistakes in taking care of your diabetes.</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>
DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by circling:

0 if it is never a problem
1 if it is almost never a problem
2 if it is sometimes a problem
3 if it is often a problem
4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.
**In the past **ONE month, **how much of a problem** has this been for you ...**

<table>
<thead>
<tr>
<th>ABOUT MY HEALTH AND ACTIVITIES (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard for me to walk more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. It is hard for me to run</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. It is hard for me to do sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. It is hard for me to lift something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. It is hard for me to take a bath or shower by myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. It is hard for me to do chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I hurt or ache</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I have low energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABOUT MY FEELINGS (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I feel sad or blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I feel angry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I have trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I worry about what will happen to me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW I GET ALONG WITH OTHERS (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have trouble getting along with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other kids do not want to be my friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Other kids tease me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I cannot do things that other kids my age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. It is hard to keep up when I play with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>ABOUT SCHOOL <em>(problems with…)</em></td>
<td>Never</td>
<td>Almost Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Almost Always</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------</td>
<td>--------------</td>
<td>-----------</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>1. It is hard to pay attention in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I forget things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I have trouble keeping up with my schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I miss school because of not feeling well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I miss school to go to the doctor or hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
EQ-5D-Y

**Describing your health TODAY**

Please check the ONE box that best describes your health TODAY

**Mobility (walking around)**
- I have **no** problems walking around
- I have **some** problems walking around
- I have **a lot** of problems walking around

**Taking care of myself**
- I have **no** problems taking a bath or shower by myself or getting dressed by myself
- I have **some** problems taking a bath or shower by myself or getting dressed by myself
- I have **a lot** of problems taking a bath or shower by myself or getting dressed by myself

**Doing usual activities** *(for example, going to school, hobbies, sports, playing, doing things with family or friends)*
- I have **no** problems doing my usual activities
- I have **some** problems doing my usual activities
- I have **a lot** of problems doing my usual activities

**Having pain or discomfort**
- I have **no** pain or discomfort
- I have **some** pain or discomfort
- I have **a lot** of pain or discomfort

**Feeling worried, sad, or unhappy**
- I am **not** worried, sad, or unhappy
- I am **a little** worried, sad, or unhappy
- I am **very** worried, sad, or unhappy
How good is your health TODAY

The best health you can imagine

- 100
- 95
- 90
- 85
- 80
- 75
- 70

The worst health you can imagine

- 0
- 5
- 10
- 15
- 20
- 25
- 30
- 35
- 40
- 45
- 50
- 55
- 60
- 65

- We would like to know how good or bad your health is TODAY.
- This line is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Please mark an X on the line to show how good or bad your health is TODAY.
APPENDIX B: MATERIALS FOR DIABETES CLINICS

Includes:

1. Study Flyer + Parental Consent Form – In person
2. Information Sheet – In person
3. Example Survey Questions – In person
4. Adolescent Assent Form – In person
Will Your Family Help Us Learn More about Life Factors in T1DM?

Dear Parent,

I am a graduate student at the University of Mississippi with a sincere passion for understanding factors that affect the quality of the lives of young people living with Type I Diabetes Mellitus (T1DM). Much has been explored with respect to clinical factors in this population (things affecting their blood glucose levels, etc.). But what about the impact of day-to-day nonclinical issues (social factors, perceived stress, etc.)?

Where Do You Fit into This?

My dissertation aims to understand adolescents’ (11-16 years) views about having T1DM and its impact on their health-related quality of life. My inquiry began this Spring, with a small group discussion among young people attending the Diabetes Youth Council Retreat at a camp in Oxford, MS. In their company, I learned quite a bit about how adolescents perceive their diabetes management and its impact on their day to day life. Building on what they have shared with me, I now seek to survey a larger group of adolescents with T1DM, to gain broader insights.

I need your permission to survey your child. (Please read the directions provided in the email.)

The responses your child might provide on this survey would be very valuable in expanding our understanding of living with T1DM as a youth. More information about the study is available in the attached information sheet. If you agree, your child will be invited to voluntarily participate in the survey. His/her choosing not to participate will not affect any current or future relationships with this diabetes clinic.

Should you (or your child) have any questions or require any further details, please feel free to contact me at (662) 202-2779 or zzshahpu@go.olemiss.edu or my research advisor, Dr. Alicia Bouldin at (662) 915-6956 or abouldin@olemiss.edu. If you consent to your child participating in this research, please sign the consent form on the back of this sheet.

What May Result from Your Child’s Participation?

It is hoped that this study may provide insight to help improve the future quality of the lives of young people living with T1DM. By combining the voices of attendees from several camps, we hope to gain a clearer image of the impact of T1DM on day-to-day issues beyond the clinical ones (e.g., glucose control).
This research has been approved by the Institutional Review Board at the University of Mississippi. If you have any questions, concerns, or reports regarding your child’s rights as a participant of this research, please contact the IRB at (662) 915-7482.

Thank you.

Zainab Shahpurwala
# PARENTAL CONSENT FORM

Below are some example questions that your child will potentially respond to on the survey. Each set of questions has a different response format (not depicted here). Sufficient instructions will be provided so that your child can appropriately answer the questions included in the survey. Surveys will be filled and collected on site. Your child’s responses will not include any identifying information (e.g., their name, address, etc.), and will only be reported as part of the entire set.

<table>
<thead>
<tr>
<th>Parental Involvement</th>
<th>Diabetes Self-management</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a parent who . . .</td>
<td>How sure are you that you can do each of the following, almost all the time?</td>
</tr>
<tr>
<td>1. Helps me plan my diabetes care to fit my schedule.</td>
<td>1. Adjust your insulin correctly when you eat more or less than usual.</td>
</tr>
<tr>
<td>2. Knows when I need a little extra help with my diabetes.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived Stress</th>
<th>Health-related Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last month …</td>
<td>In the past month, how much of a problem has this been for you …</td>
</tr>
<tr>
<td>1. How often have you been able to control irritations in your life?</td>
<td>1. I have low energy</td>
</tr>
<tr>
<td>2. How often have you felt that you were on top of things?</td>
<td>2. I have trouble sleeping</td>
</tr>
</tbody>
</table>

**Directions:** Read each of the statements below and place a check mark in the adjacent boxes (☑) indicating that you have understood what the research is about and your decision to allow your child to participate in this study.

- [ ] I understand that my child does not have to take part in this study and that my refusal to let my child participate will involve no penalty or loss of rights to which my child and/or I are entitled.
- [ ] I further understand that my child is free to later withdraw my consent (and his/her assent) and discontinue participation in this study at any time.
- [ ] I understand that refusing to participate or later withdrawing from the study will not adversely affect my child’s and/or my subsequent relationship with this diabetes clinic.
- [ ] I confirm that the investigator has answered all of the questions I have at this time regarding the study and my child’s rights as a participant of this research.
- [ ] I freely consent to my child’s participation in the study.

**Please SIGN below:**

_________________________    __________________________    ____________
Signature of Parent          Printed name           Date

**NOTE TO PARTICIPANTS:** (1) DO NOT SIGN THIS FORM IF THE IRB APPROVAL STAMP ON THIS PAGE HAS EXPIRED. (2) A COPY OF THIS CONSENT FORM WILL BE PROVIDED TO YOU.
INFORMATION SHEET FOR PARENTS

What is the study about?

- The study wants to understand adolescents’ thoughts about having diabetes, how they manage their diabetes, and how having diabetes impacts their day to day life.

Who can take part?

- Young people, aged 11 to 16 years, with Type 1 Diabetes can take part.

Does your child have to participate?

- No. It is completely up to you and your child to decide if you’d like to be part of this study.
- If you do decide to participate, you and your child are free to stop at any time during the study without giving any reasons. Deciding not to participate will not affect your relationship with anyone at this diabetes clinic or at The University of Mississippi.

What are the possible benefits of taking part?

- There are no direct medical benefits for taking part in this study. Participation may provide indirect benefit to your child and others by improving our understanding of T1DM management in adolescents.

What are the possible disadvantages of taking part?

- There are no risks involved. If taking part in the study causes your child discomfort of any sort, contact the researcher right away.

What happens to the information?

- All the information provided by your child during the study will be kept strictly confidential (private). The results of this study will be reported in a professional journal and will also be available at this diabetes clinic and everyone who takes part.

If your child does take part, what will happen?

- Your child will be asked to indicate their willingness to participate by signature. Please contact us with any questions (see contact details below).
- Your child will be asked to fill out a questionnaire at the diabetes clinic before or after their scheduled appointment. It should take no longer than 30 minutes to complete the questionnaire.
What if there’s a problem?

- You and your child can use the contact details listed below to get in touch with the researcher at any time before, during, or after completing the study.
- **Contact details:**
  - Investigator: Zainab Shahpurwala
    - Tel: (662) 202-2779
    - Email: zsshahpu@go.olemiss.edu
YOUNG PERSON ASSENT FORM

Directions: Read each of the statements below and place a check mark in the adjacent boxes (☑) indicating that you understand what the research is about and your decision to participate in this study.

☐ I understand that I do not have to take part in this study and that my refusal to participate will involve no penalty or loss of rights to which I am entitled.

☐ I further understand that I am free to later withdraw my assent and discontinue participation in this study at any time.

☐ I understand that refusing to participate or later withdrawing from the study will not adversely affect my subsequent relationship with this diabetes clinic.

☐ I understand that if I take part in this research I will be asked to answer questions regarding my diabetes and its impact on my day to day life by filling out a survey.

☐ I further understand that the survey will take no longer than 30 minutes to complete.

☐ I confirm that the investigator has answered all of the questions I have at this time regarding the study and my rights as a participant of this research.

☐ I freely volunteer to participate in the study.

Please SIGN below:

_________________________  ___________________________  ________
Signature of Young Person  Printed name  Date
APPENDIX C: MATERIALS FOR DIABETES CAMPS

Includes:

1. Parental Consent Email Text
2. Study Flyer – Via email
3. Information Sheet – Via email
4. Example Survey Questions – Via email
5. Parental Consent Form – In person
6. Adolescent Assent Form – In person
Dear Parent:

A research study is being conducted at Camp (Insert Name), as part of a graduate student's dissertation at The University of Mississippi. The study aims to understand adolescents’ perceptions regarding their Type 1 Diabetes Mellitus (T1DM) and its impact on their health-related quality of life. As a result, young people (aged 11 – 16 years) with T1DM are being asked to respond to a survey to discuss their experiences and thoughts about having diabetes.

As your child is planning on attending Camp (Insert Name), the responses he/she might provide there would be very valuable. More information about the study is available in the attached flyer and information sheet. Also, attached is a table of example questions that your child will potentially respond to when taking the survey.

Directions: Read each of the statements below and place an (X) mark adjacent to each of them indicating that you have understood what the research is about. Please forward this email to us at zssshahpu@go.olemiss.edu indicating your consent to allow your child to participate in this study.

I have read the flyer, information sheet and example survey questions (attached in this email) that describe the study being conducted at Camp (Insert Name).

I understand that my child does not have to take part in this study and that my refusal to let my child participate will involve no penalty or loss of rights to which my child and/or I are entitled.

I further understand that my child is free to later withdraw my consent (and his/her assent) and discontinue participation in this study at any time.

I understand that refusing to participate or later withdrawing from the study will not adversely affect my child’s and/or my subsequent relationship with Camp (Insert Name).

I confirm that the investigator has answered all of the questions I have at this time regarding the study and my child’s rights as a participant of this research.
I freely consent to my child’s participation in the study.

Your Full Name: ____________________________________________

Be assured that if you do not consent, we will ensure that your child does not participate in this research during their time at Camp (Insert Name).

Sincerely,
Zainab Shahpurwala
Doctoral Candidate
Department of Pharmacy Administration School of Pharmacy
223 Faser Hall
University of Mississippi
University, MS 38677
Tel: (662) 202-2779
Email: zsshahpu@go.olemiss.edu
Will Your Family Help Us Learn More about Life Factors in T1DM?

Dear Parent,

I am a graduate student at the University of Mississippi with a sincere passion for understanding factors that affect the quality of the lives of young people living with Type I Diabetes Mellitus (T1DM). Much has been explored with respect to clinical factors in this population (things affecting their blood glucose levels, etc.). But what about the impact of day-to-day nonclinical issues (social factors, perceived stress, etc.)?

Where Do You Fit into This?

My dissertation aims to understand adolescents’ (11-16 years) views about having T1DM and its impact on their health-related quality of life. My inquiry began this Spring, with a small group discussion among young people attending the Diabetes Youth Council Retreat at a camp in Oxford, MS. In their company, I learned quite a bit about how adolescents perceive their diabetes management and its impact on their day to day life. Building on what they have shared with me, I now seek to survey a larger group of adolescents with T1DM, to gain broader insights.

I need your permission to survey your child. (Please read the directions provided in the email.)

Why Are We Interested in Camp-goers?

A diabetes summer camp, where attendees are among their peers in a familiar and safe environment, is an ideal place to survey young people with T1DM to assess their views about their condition. The time needed is very short (one 30-minute block) and will not interfere with planned camp activities. Several camps across the Southeast, including Camp (Insert Name) in (Insert Location), are allowing me to survey attendees during their diabetes summer camps this July.

The responses your child might provide on this survey would be very valuable in expanding our understanding of living with T1DM as a youth. More information about the study is available in the attached information sheet. If you agree, your child will be invited to voluntarily participate in the survey. His/her choosing not to participate will not affect any current or future relationships with Camp (Insert Name). Should you (or your child) have any questions or require any further details, please feel free to contact me at (662) 202-2779 or zsshahpu@go.olemiss.edu or my research advisor, Dr. Alicia Bouldin at (662) 915-6956 or abouldin@olemiss.edu. If you consent to your child participating in this research, please follow the directions given in the email in order to provide your consent.

What May Result from Your Child’s Participation?

It is hoped that this study may provide insight to help improve the future quality of the lives
of young people living with T1DM. The study may even reveal the importance of diabetes camps in the lives of attendees, a factor that has been suggested anecdotally. By combining the voices of attendees from several camps, we hope to gain a clearer image of the impact of T1DM on day-to-day issues beyond the clinical ones (e.g., glucose control).

This research has been approved by the Institutional Review Board at the University of Mississippi. If you have any questions, concerns, or reports regarding your child’s rights as a participant of this research, please contact the IRB at (662) 915-7482.

Thank you.

Zainab Shahpurwala
INFORMATION SHEET FOR PARENTS

What is the study about?

➢ The study wants to understand adolescents' thoughts about having diabetes, how they manage their diabetes, and how having diabetes impacts their day to day life.

Who can take part?

➢ Young people, aged 11 to 16 years, with Type 1 Diabetes can take part.

Does your child have to participate?

➢ No. It is completely up to you and your child to decide if you’d like to be part of this study.
➢ If you do decide to participate, you and your child are free to stop at any time during the study without giving any reasons. Deciding not to participate will not affect your relationship with anyone at Camp (Insert Name) or at The University of Mississippi.

What are the possible benefits of taking part?

➢ There are no direct medical benefits for taking part in this study. Participation may provide indirect benefit to your child and others by improving our understanding of T1DM management in adolescents.

What are the possible disadvantages of taking part?

➢ There are no risks involved. If taking part in the study causes your child discomfort of any sort, contact the researcher right away.

What happens to the information?

➢ All the information provided by your child during the study will be kept strictly confidential (private). The results of this study will be reported in a professional journal and will also be available at this diabetes clinic and everyone who takes part.

If your child does take part, what will happen?

➢ Your child will be asked to indicate their willingness to participate by signature. Please contact us with any questions (see contact details below).
➢ Your child will be asked to fill out a questionnaire at the diabetes clinic before or after their scheduled appointment. It should take no longer than 30 minutes to complete the questionnaire.
What if there’s a problem?

- You and your child can use the contact details listed below to get in touch with the researcher at any time before, during, or after completing the study.

Contact details:
Investigator: Zainab Shahpurwala
Tel: (662) 202-2779
Email: zsshahpu@go.olemiss.edu
EXAMPLE SURVEY QUESTIONS

Below are some example questions that your child will potentially respond to on the survey. Each set of questions has a different response format (not depicted here). Sufficient instructions will be provided so that your child can appropriately answer the questions included in the survey. Surveys will be filled and collected on site. Your child’s responses will not include any identifying information (e.g., their name, address, etc.), and will only be reported as part of the entire set. The investigator will be present to answer any questions or address any concerns your child might have when taking the survey.

<table>
<thead>
<tr>
<th>Parent Involvement</th>
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<td>How sure are you that you can do each of the following, almost all the time?</td>
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<td>1. Adjust your insulin correctly when you eat more or less than usual.</td>
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<tr>
<td>2. Knows when I need a little extra help with my diabetes.</td>
<td>2. Choose healthful foods when you go out to eat.</td>
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<th>Perceived Stress Scale</th>
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<td>In the last month …</td>
<td>In the past month, how much of a problem has this been for you …</td>
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<td>1. How often have you been able to control irritations in your life?</td>
<td>1. I have low energy</td>
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I need your permission to survey your child. (Please see the back of this form.)

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Thank you.

Zainab Shahpurwala

**Please see the other side for additional content**
PARENTAL CONSENT FORM (IN-PERSON)

Below are some example questions that your child will potentially respond to on the survey. Each set of questions has a different response format (not depicted here). Sufficient instructions will be provided so that your child can appropriately answer the questions included in the survey. Surveys will be filled and collected on site. Your child’s responses will not include any identifying information (e.g., their name, address, etc.), and will only be reported as part of the entire set. The investigator will be present to answer any questions or address any concerns your child might have when taking the survey.

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Directions: Read each of the statements below and place a check mark in the adjacent boxes (☑) indicating that you have understood what the research is about and your decision to allow your child to participate in this study.

- ☐ I understand that my child does not have to take part in this study and that my refusal to let my child participate will involve no penalty or loss of rights to which my child and/or I are entitled.
- ☐ I further understand that my child is free to later withdraw my consent (and his/her assent) and discontinue participation in this study at any time.
- ☐ I understand that refusing to participate or later withdrawing from the study will not adversely affect my child’s and/or my subsequent relationship with Camp (Insert Name).
- ☐ I confirm that the investigator has answered all of the questions I have at this time regarding the study and my child’s rights as a participant of this research.
- ☐ I freely consent to my child’s participation in the study.

Please SIGN below:

_____________  ___________________  ________
Signature of Parent Printed name Date

NOTE TO PARTICIPANTS: (1) DO NOT SIGN THIS FORM IF THE IRB APPROVAL STAMP ON THIS PAGE HAS EXPIRED. (2) A COPY OF THIS CONSENT FORM WILL BE PROVIDED TO YOU.
YOUNG PERSON ASSENT FORM

Directions: Read each of the statements below and place a check mark in the adjacent boxes (√) indicating that you understand what the research is about and your decision to participate in this study.

☐ I understand that I do not have to take part in this study and that my refusal to participate will involve no penalty or loss of rights to which I am entitled.

☐ I further understand that I am free to later withdraw my assent and discontinue participation in this study at any time.

☐ I understand that refusing to participate or later withdrawing from the study will not adversely affect my subsequent relationship with Camp (Insert Name).

☐ I understand that if I take part in this research I will be asked to answer questions regarding my diabetes and its impact on my day to day life by filling out a survey.

☐ I further understand that the survey will take no longer than 30 minutes to complete.

☐ I confirm that the investigator has answered all of the questions I have at this time regarding the study and my rights as a participant of this research.

☐ I freely volunteer to participate in the study.

Please SIGN below:

_________________________  ___________________________  ______________
Signature of Young Printed name Date
Person

143
VITA

Zainab S. Shahpurwala was born on June 5, 1986. After graduating from Jai Hind College in Mumbai, India, in 2004, she enrolled in the University Institute of Chemical Technology School of Pharmacy. In June 2008, Zainab received a Bachelor of Pharmacy degree with emphasis in pharmaceutical sciences and is a registered pharmacist in Maharashtra, India. In the fall of 2009, she began attending the University of Mississippi School of Pharmacy for graduate education in Pharmacy Administration and received her Master of Science degree from the program in November 2011.

Zainab has served as an assistant in both teaching and research capacities while completing the requirements of the Doctor of Philosophy degree (December 2015), majoring in Pharmacy Administration. Her research interests include patient, consumer and provider behavior, patient reported outcomes, and health economics and outcomes research.

During her time in the graduate program Zainab has been invited to join a number of honor societies including Phi Kappa Phi, Rho Chi and Who’s Who Among Students in American Universities and Colleges. She also plays an active role in a number of on campus organizations at the University of Mississippi.