January 2013

Parent Distress in Life with a Child with Type 1 Diabetes

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Parent Distress in Life with a Child with Type 1 Diabetes

by

Lauren Nicole Johnson

A dissertation proposal submitted in partial fulfillment
of the requirements for the degree of
Doctor of Public Health
Department of Community and Family Health
College of Public Health
University of South Florida

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Date of Approval:
   June 27, 2013

Keywords: Parent / Child Relation, Stress, Coping, Anxiety, Depression

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DEDICATION

For my darling daughter Ava, always remember that you can do anything no matter how hard it seems.

For my parents, George and Emily, who battle life with a child with diabetes every day, thank you.
ACKNOWLEDGMENTS

My heartfelt thanks to my advisor Dr. Julie Baldwin and the members of my committee for teaching and shepherding me through the dissertation process. Without their help, this work would not have been possible and I am forever grateful for the education and support they provided.

The professionals at the Behavioral Diabetes Institute played a significant role in this project and are due great thanks. I deeply appreciate their patience and faith.

Stephanie Melton also played a significant role in the qualitative portion of this project. My deep thanks and appreciation for her efforts and support.

The USF Evidence Based Medicine group provided valuable input, support, and assistance with the statistical analysis in this research. Their efforts are so appreciated.

This project is rich because of the people who shared their stories and wishes with me. To those living with diabetes that participated, I admire your courage, envy your strength, and am thankful for your friendship.
The biggest thank you, though, goes to my family and especially my daughter Ava. She was my inspiration throughout the entire process.
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ABSTRACT

Objective:

The purpose of this study was to highlight parent distress in diabetes, identify factors associated with distress and to show how public health and clinical professionals can assist parents in coping with their child’s diabetes and living positively as a family unit.

Methods:

Parents of youth with diabetes (N = 41 qualitative, N = 332 quantitative) were engaged in focus groups, interviews, and survey research to understand their needs and stressors in life with a child with diabetes. Themes were examined in the qualitative data, and correlations and a regression model were run and analyzed from the quantitative data set, made available by the Behavioral Diabetes Institute.

Results:

The results of the study suggested that parents who were more isolated, have tense relationships with youth, and have greater family conflict are most likely to report high levels of distress. Parents shared that they experience great fear related to life with diabetes and describe the fear as “constant” and “unrelenting.” Most parents experienced frustration related to life with diabetes, yet the frustration changes with time and disease experience. Distress was more
common in mothers, as well as in younger parents. Distress was also shown to correlate with duration of disease and younger parent age.

**Discussion:**

Distress is a part of life with diabetes, both for the person with diabetes and their caregivers. Parent distress is particularly challenging as it includes the delicate balance between the parent being the life support for the child with diabetes and the parent learning to let go of the same child in the maturation process. Parents face difficulties knowing how to assist their child proactively without creating a negative family dynamic. There is opportunity for health professionals to intervene in the family experience in life with diabetes.

Health professionals should be aware of the kind of distress families are experiencing, the environment in which the family lives and functions, and the coping mechanisms used by each person in the family with diabetes. Understanding parenting style would be useful in identifying parents that may need extra support and education about living with and helping their child with diabetes. Shifts in the diabetes education practices around diabetes would also benefit families. More emphasis on family dynamics in clinical environments would provide greater understanding for health professionals about family functioning and diabetes distress.
CHAPTER ONE

Introduction

The plight of youth and families coping with type 1 diabetes is significant. The stress of physical management, social adaption, emotional health, and life normalcy are tremendous and constant. The disease never goes into remission and never takes a day off. In light of the pervasiveness of diabetes in the U.S., (8.3% of the population or over 26 million individuals) and the economic impact of the disease ($174 billion annually), public health professionals must take action to bring prevention and broad research wisdom to the conversation about how to improve overall health and wellbeing in people with and those affected by diabetes (CDC Diabetes Fact Sheet, 2011). In 2012, the CDC noted, “an important role of public health is identifying community preventive services that are effective in increasing the use of clinical preventive services” (CDC, June 15, 2012). This statement reflects the broad purpose of this research: to contribute to the improvement of the quality of life of people living with and impacted by diabetes. The specific population of interest is parents of youth with type 1 diabetes. The subpopulation of youth with type 1 diabetes is small (prevalence of 1.8 per 1000 children), but the research will show the importance of interventions that target caregivers and ultimately impact the youth with disease (CDC Children and Diabetes, 2011). Much has been written about family functioning and diabetes management (Akbas et al., 2009; Cohen et al., 2004; Hanna et al., 2003). It is well known that positive family environments promote better diabetes care and outcomes, while family conflict, including stress, predicts poor diabetes outcomes (Williams, 2009). Less is known about how to predict which families will experience distress related to life
with diabetes, what coping mechanisms families use in dealing with distress, and how health professionals could best assist such families. Public health professionals can play a significant role here. Use of public health skills in planning effective collaborations, designing community interventions, and creating useful tools can aid in meeting the overall goals of improved clinical and quality of life outcomes.

**Significance of the Topic**

JDRF, formerly the Juvenile Diabetes Research Foundation, estimates that approximately 3 million people have type 1 diabetes (JDRF, 2012). These individuals must use insulin daily for survival. However, physical survival is only part of the battle in life with this kind of chronic illness; there are also emotional and psychological challenges that accompany the disease. Research suggests that to achieve success in managing diabetes and the psychosocial issues associated with youth, especially adolescents with type 1 diabetes, health professionals should promote self-efficacy, interpersonal support, depression prevention, and effective coping strategies (Akbas et al., 2009; Hanna et al., 2003). Strategies appropriate in executing this type of care include education for friends and family related to attitudes and behaviors associated with the young person’s diabetes, and depression/distress assessment for the person with diabetes, as well as for the support team surrounding that person (Kipps et al., 2002).

The care and management of diabetes is a gargantuan task. Diabetes care currently tends to focus on clinical outcomes, with blood glucose readings and A1c values as the measures of success. People living with diabetes observe, however, that there is much more to the creation of a successful life with diabetes than clinical measures. Likewise, the person with diabetes is not the only person who may require care and attention: family members and caregivers are also part
of the formula (Anderson, 2003; Beveridge et al., 2006; Cunningham et al., 2011; Hegelson et al., 2008; Mednick et al., 2007; Sander et al., 2010).

**Need for the Study**

The evidence from current research shows that intimate relationships have a direct affect on health outcomes (Anderson, 2003). Therefore, it is necessary that the patient’s clinical issues be considered in the context of his/her social systems. The combination of factors, personal and social, contribute to individual health behaviors and outcomes. In this social ecological view of diabetes, family relationships become a natural starting place to improve health and well being.

This research explores aspects of family relationships as they may affect and be affected by clinical, social, and other realities of raising a child with diabetes. Specifically, parent feelings about clinical encounters, parent concerns about raising a child with diabetes, and parent unmet needs are studied by using a mixed methods design of qualitative and quantitative approaches.

The qualitative research component focused on gaining a deep understanding of parent feelings regarding life with a child with diabetes. Data were obtained from parents of youth with diabetes age 10-25 in the Tampa Bay region for this portion of the research. The qualitative section of the results will highlight quotes from parents on what they feel would make their lives with diabetes better. The objective was to allow the parent’s voice to be heard and the distress of the family to be recognized. As one parent noted, this research highlights the “chronic sadness of life with diabetes” for caregivers (Interviewee, 2011).

The quantitative component of this study examined data obtained from the Parent Diabetes Distress Scale and an accompanying battery of validated questionnaires made available by the Behavioral Diabetes Institute (BDI). The questionnaires, distributed by both BDI and the
researcher for the purpose of both this research and the creation of the final version of the Parent Diabetes Distress Scale, gathered a data set of 332 respondents from across the United States. In this study, associations between parent distress, parenting style, parent self-efficacy, parent disagreement, and parent emotional support were examined.

**Purpose of the Study**

The purpose of this study was to highlight parent distress in diabetes, identify factors associated with distress, and to show how professionals, public health and clinicians, can assist parents in coping with their child’s diabetes and living positively as a family unit. The stress of diabetes management and the specific stresses parents experience as they walk the diabetes tightrope of life and death with their child often have negative outcomes. Increased parental involvement in diabetes care typically results in improved outcomes, but it can also cause conflict within the family, which can negatively impact youth adherence to diabetes self-care behaviors (Sander et al, 2010). As parents feel excessive concern, many tend to express care through what is perceived by youth as nagging, resulting in further family conflict (Kakleas et al., 2009). Thus, family conflict has been associated with lower youth self-efficacy and less frequent glucose monitoring (Sander et al., 2010).

There is no single, best family dynamics model for families living with diabetes. But it is clear that the consideration of family functioning, family coping, and parental stress are important factors in diabetes care and additional study of these dynamics can contribute to improved quality of care and quality of life for diabetes families.
Clinical Significance

Parents of youth with diabetes experience varying levels of distress throughout the life course. Parent distress has been largely unrecognized and in most cases untreated. By recognizing the type of distress parents are under and the characteristics of parents who experience the most distress, health professionals can be equipped to better serve families and therefore influence outcomes for both the family and the child with diabetes.

Depression assessments are common in clinical care, but specific distress assessments are not. This study highlights how health professionals can provide assistance to families with the knowledge of factors that influence distress and the availability of distress assessment instruments.

Research Questions

To best understand parent distress in life with a child with diabetes, qualitative and quantitative questions have been posed in this research. The qualitative questions were mostly associated with parent perspectives on life with a child with diabetes. The quantitative questions sought to identify linkages between distress and parenting style, parent self-efficacy, parent disagreement, and parent emotional support.

Qualitative Research Questions

To understand the challenges and needs of parents living with a child with diabetes:

• What are parent needs (met and unmet) when raising a child with diabetes?
• What challenges do parents face in life with diabetes?
• What strategies are most helpful for parents working to help manage their child’s diabetes?
**Quantitative Research Questions**

- What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?
- To what degree, if at all, is parent self-efficacy associated with parent diabetes-related distress?
- To what degree, if at all, is parent emotional support associated with parent diabetes-related distress?
- To what degree, if at all, is parent disagreement associated with parent diabetes-related distress?
- To what degree, if at all, is parenting style associated with parent diabetes-related distress?

In this research, the quantitative data set used questionnaires about: parent self-efficacy, defined as how confident parents are about their own and their child’s diabetes knowledge; parent emotional support, indicating how supported parents feel; parent disagreement, to better understand parents who share responsibility for diabetes management; parenting style, an assessment of authoritarian, authoritative, or permissive parenting beliefs based on responses to parenting belief questions; and parent diabetes-related distress, a mean score derived from the Parent Diabetes Distress Scale questionnaire.

**Study Delimitations**

The participants for this study included two convenience samples of individuals who each included individuals connected to diabetes by family relation. The subjects of each sample were
caregivers of youth with type 1 diabetes and the samples both included participants from the Tampa Bay region. The quantitative sample was, however, more broad than the qualitative, as it had a national scope. The subjects in each sample self-identified and volunteered to participate in the research through individual response to advertisements, requests from health providers, and messages from non-profit organization partners.

This study also considered the unique family factors of extended relatives serving as the child’s primary caregiver, such as grandparents who are serving as guardians. These caregivers were presumed to be equally emotionally tied to the youth with disease as biological parents would be, and thus were assumed to experience the same levels of distress as the traditional parent participants.

The literature review explored challenges facing families living with a child with diabetes including: depression, psychological adjustment, post-traumatic stress, and role strain. The findings on factors associated with distress grounded the study, particularly with respect to the complexity of family dynamics. The literature review covered relevant diabetes literature over a 10 year period and written in the English language. The decision to limit the literature search was made keeping in mind that the issues addressed in this research have become more prevalent during the last decade.

The quantitative data set used in this study consisted of information from a convenience sample of 332 individuals from across the U.S., who self-identified as parents of teens with type 1 diabetes. This information was viewed as secondary data since it was collected prior to this specific study and was not explicitly collected for the purposes of only this study. The data were examined uniquely for the purpose of this investigation according to a standardized protocol.
The qualitative portion of this study was conducted in the Tampa Bay region. A wide range of families and family experiences were explored and documented using semi-structured focus groups in an effort to identify common themes and issues of concern. Saturation was met at 41 participants, as duplicate information was being provided frequently to the researchers and no new information emerged during the last several interviews and the final three focus groups.

**Study Limitations**

One of the main limitations of this study was the use of a convenience sample, which may lead to selection bias. The individuals interviewed in the Tampa Bay region, and the participants nationwide who completed the battery of questionnaires related to parent diabetes distress self-identified and therefore may not be representative of the population of parents who have a child with diabetes.

The researcher also may have introduced bias due to her personal experiences with type 1 diabetes. This bias was most likely reflected in the qualitative portion of the study because the researcher led the conversations with parents. However, the researcher was cognizant of this challenge and relied on self-reflexivity and assistance from another non-biased researcher who participated in each interview to watch for and guard against the introduction of interviewer bias.

The use of the secondary data gathered from a large battery of questionnaires used to validate the PDDS is another study limitation. Because the original qualitative data contributed to the creation of the pilot PDDS, there was a chance for carryover of interviewer bias. However, the potential bias with the PDDS instrument was offset by expert review throughout the various phases of creation of the instrument. Several noted psychologists and health professionals with experience in diabetes analyzed the instrument and reviewed it for consistency and soundness
throughout the process.

The data set has been used previously for other studies and has been presented at scientific meetings in a context different from this specific research. For this study, the use of the secondary data can be justified because of the exploratory nature of the study (hypothesis generation and not testing) and the uniqueness and relevance of the data set to the research questions.

Practical data challenges always pose limitations in mixed methods studies. The mixed method design can be time consuming, can require much effort, and can cause significant cost. However, the design can also be considered a strength. The complexity of the mixed method analysis provides greater depth of understanding.

**Definition of Relevant Terms**

*Type 1 Diabetes*: Type 1 diabetes was once known as juvenile diabetes or insulin-dependent diabetes. It is a chronic condition where the pancreas does not produce insulin adequate for survival (Mayo Clinic, 2012).

*Distress*: Merriam-Webster dictionary defines distress in multiple ways. The most appropriate for this work are definitions 2a, b and 3: “pain or suffering affecting the body, a bodily part or the mind”; “a painful situation”; “a state of danger or desperate need”. Distress is also noted in medical terms as “a situation where the person is unable to adapt completely to the stressors at
hand and their resulting stress and shows maladaptive behaviors.” (Merriam-Webster, 2012).

http://www.merriam-webster.com/dictionary/distress

**HbA1c or A1c:** The HcA1c or more commonly called the A1c, is a lab test that shows the average level of blood sugar over the previous 3 months (Medline Plus, 2012). This average is used as an indicator of diabetes control.


**JDRF – formerly the Juvenile Diabetes Research Foundation:** JDRF is the leading organization focused on type 1 diabetes. Their purpose is to fund research to cure diabetes. Recently, the organization has begun to look more deeply at psychosocial aspects of care and complications for those living with type 1 diabetes. Since it’s founding in 1970, JDRF has awarded more than $1.6 billion to diabetes research (www.jdrf.org).

**American Diabetes Association (ADA):** The American Diabetes Association (ADA) is a clinical and patient organization that services all aspects of diabetes. Their tag line is “Cure, Care, Commitment”. This organization is heavily involved in advocacy and protecting the rights of individuals living with diabetes. www.diabetes.org

**Atlas ti:** Atlas ti is a computer software program that was used for the qualitative analysis. This software assists researchers in coding, locating and sorting large amounts of information, videos, audio files and graphical data.
SPSS: “IBM SPSS Statistics software is an integrated family of products that addresses the entire analytical process, from planning to data collection to analysis, reporting and deployment.”

www-01.ibm.com/software.analytics/spss/products/statistics/
CHAPTER TWO

Literature Review and Theoretical Approach

Background

This chapter summarizes a systematic review of the literature conducted to examine the prevalence of distress in parents of children who have type 1 diabetes, major contributors to parent distress, and the relationship between parent diabetes expectations and distress.

The collection of literature here provided a modern perspective on the issue of parent distress in life with a child with diabetes. All the articles included were published within the last 10 years and thus benefit from post Diabetes Control and Complications Trial (DCCT) data and philosophy (The Diabetes Control and Complications Trial Research Group, 1993). The DCCT was landmark research that changed the course of diabetes care for people on insulin. Since the DCCT, individuals with type 1 diabetes have been intensively managed (insulin pumps or multiple daily injections) and have been advised to seek blood glucose levels in a “normal range” indicated by HbA1c values between 6-7% (The Diabetes Control and Complications Trial Research Group, 1993).

Recognizing the multiple challenges facing parents/caregivers of youth with type 1 diabetes, a systematic look at what the literature tells us about their distress and coping was beneficial to move research forward to broad implementation in both clinical and community settings. Throughout the review, the literature demonstrated the need for interventions focused on caregivers. This summary was by no means a comprehensive look at these issues, but rather
an overview of key points in the literature with commentary highlighting the importance of investigating distress and coping in the context of the questions being considered.

The importance of family relationships was evident throughout the research literature, yet it has not been fully integrated into current clinical practice. Anderson noted in 2003 that, “More than any other chronic physical illness, the management of diabetes is under the control of the patient” (p.134). Here, the literature demonstrated how the family unit or intimate relationships are equally strained, as is the individual’s own emotional wellbeing in the course of diabetes management (Anderson, 2003). Anderson engaged a social ecological view in her article and showed why it is necessary to consider the patient in the context of his/her social systems and how those systems impact health behaviors.

**Synthesis of the Literature**

The majority of articles noted depression or depressive states, family conflict, adherence issues/diabetes management, and the responsibility/burden of diabetes as contributors to parent distress. From existing research, we know that if there is any lack of cohesion between parents related to diabetes management, diabetes related tasks, and diabetes responsibility, the likelihood of parent distress is higher (Jaser et al., 2008). This collection of literature seemed to reinforce that a significant challenge for parents is determining a family system of shared responsibility and role definitions related to diabetes in the family (Jaser et al., 2011).

This review, looked intently at depression, parent psychological stress, role strain, and parent expectations as topics that partially answer the questions set forth about factors associated with distress. The information from the articles examined showed that parental stress can be caused by multiple factors and can be potentially dangerous for all members of the family if not
managed (Whittemore et al., 2012). The literature indicated that parent distress is common, mostly untreated, and an area of great need and opportunity.

Missing in the data reviewed is an explicit look at parent distress and how that distress can be linked to caregiver behaviors. Current research does not provide the insights needed to help parents understand and modify their behaviors and their approach to their child’s diabetes.

**Depression**

A dominant theme throughout the literature was the connection between depression and family coping. The literature pointed to numerous suggestions and conclusions related to this delicate scenario. Recommendations range from gender specific findings, to the link between depression and fear, to parenting style, and then to parenting behaviors. (Butler, Skinner, Gelfand, Berg, & Wiebe, 2007; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009; Jaser & Grey, 2010). Maternal depression was more commonly cited in the literature than paternal depression (Jaser et al., 2009). Maternal depression was often linked to fear of hypoglycemia, the intensity of lifestyle changes for the family, and lower levels of child-centered (authoritative) parenting or diabetes burnout (Jaser et al.,2009; Jaser, 2010). Eckshtain (2010) also indicated that parents with depressive symptoms were more likely to practice ineffective parenting techniques or to employ ineffective parenting styles. These connections between depressive states and parenting behaviors specifically tie to the research questions proposed. Thus, parenting style may be an important consideration in identifying which parents are in the greatest need.

Another association drawn in the literature was between diabetes, parent depression, and parent perception of the diabetes burden in the family (Cunningham, Vesco, Dolan, & Hood, 2011). This contributed to thoughts around depression and role definitions. For example, Hegelson (2008) recognized that shared responsibility regarding diabetes can help reduce
depressive symptoms. Lindstrom (2011) showed that performance based self-esteem (often diabetes tasks) seemed to connect to symptoms of diabetes burnout and depression. At times, this could be seen when parents base their parental effectiveness on their child’s diabetes outcomes (blood sugar or HbA1c). These articles suggested the need to clearly define roles and responsibilities for diabetes care in families from the beginning of life with the disease to potentially avoid depressive symptoms throughout the disease experience.

When considering intervention strategies, most articles suggested that depression screenings for parents/caregivers in the clinical setting would be beneficial in helping families cope with diabetes (Whittemore, Jaser, Chao, Jang & Grey, 2012). The knowledge of depressive states or attitudes could aid health professionals in helping parents address feelings of vulnerability, burnout, and frustration (Streisand, Mackey, Elliot, Mednick, Slaughter, Turek & Austin, 2008). Screenings for depression or distress may also provide health professionals insight into family functioning, as well as clues to potential behavior concerns in the family unit. Such screenings could be considered preventive strategies for families.

Depression was also discussed frequently from the perspective of youth and how parent behaviors impacted youth perspectives of disease. Butler (2007) found that “maternal acceptance lead to lower depressive mood and higher self-efficacy” (p. 1233). Likewise, Botello-Harbaum (2008) indicated responsive (authoritative) parenting was closely linked to positive youth health perceptions and optimism.

It is understandable that depression and depressive symptoms might accompany the diagnosis of a life threatening childhood illness. The literature pointed to many recommendations for interventions aimed at the family unit. It seemed that addressing challenges regarding psychological stress and role strain in particular might aid in the reduction of the
frequency of depressive symptoms in parents and families (Haugsvedt, Wentzel-Larsen, Rokne & Graue, 2011). Steps should be considered to creatively incorporate the findings from depression related research into clinical settings to test impact and efficacy.

The repeated use of the Center for Epidemiological Studies Depression Scale in this literature review was an indicator of the intensified interest in the topic of caregiver strain and depression in diabetes. From the review matrix (Appendix C), 11 articles specifically have depression related findings. Depressive symptoms in parents were associated with the risk for the use of ineffective parenting styles, could indicate lower levels of child-centered parenting practices, and may be linked to lower family collaboration and communication (Eckshtain, Ellis, Kolmodin & Naar-King, 2012; Jaser, 2011; Jaser & Grey, 2010; Berg, Weibe, Beveridge, Palmer, Korbel, Upchurch & Davidson, 2007).

Parent Psychological Stress

Other dominant themes revealed by the literature review were parent psychological stress and perceived disease burden. The emotional turmoil in the family unit can be profound. Ginsburg (2005) noted, “Parents spoke of the disappointment and shame they feel when diabetes management is not going well” (p. 1102). The physical burden of managing diabetes was often compounded with fear. The life and death nature of fear associated with diabetes and insulin played a significant role here. Fear of hypoglycemia was especially prevalent in parents (Haugsvedt et al., 2010). Haugsvedt (2011) concluded that interventions should target parent’s fear. Stressful experiences with diabetes, including parent misperceptions of youth behaviors and intentions, seemed to link to continued parental psychological stress (Haugsvedt et al., 2010; Howe et al., 2011; Whittemore et al., 2012).
Maternal stress was often noted as more significant than paternal stress (Haugsvedt et al., 2010). In the Haugsvedt article, maternal stress was linked to a higher likelihood for mothers to worry, as well as higher likelihood for mothers to be nighttime caregivers for children. An outcome of such psychological stress could be diabetes burnout. Diabetes burnout was described as when one grows so tired of the tasks related to diabetes that they engage in self-destructive and disease neglecting behaviors (Giles, 2009; Polonsky, 1999). A lack of motivation could be the end result. This psychological state tied together the themes of depression, role strain / shared decision-making, self-efficacy, and the overall burden of the emotional and physical stress that can plague parents (Lindstrom, Aman & Norber, 2011).

Psychological stress was also considered in the context of family conflict (Williams, Laffel & Hood, 2009). Williams (2009) noted family conflict also closely associated with psychological distress and could lead to negative diabetes outcomes. The goal of family engagement in diabetes is the opposite. This notion begs the question of how to help families maintain positive relationships while at the same time helping families feel confident in life with diabetes. Interestingly, Mednick (2007) took a different interventional approach as she showed that hope can be considered a potential protector against stress and anxiety and could assist families in overall coping. Further investigation into positive coping strategies would be useful in evaluating the total picture of the risks and benefits in life with diabetes and thus how to best help families live well with the disease.

**Disease Comparisons and Post Traumatic Stress**

To better understand the complexities of life with chronic illness and the stress placed on the family unit, six articles were included in this review that compared the stress of life with diabetes to other childhood illnesses (Carpentier, Mullins, Wolfe-Christensen, & Chaney, 2008;
Fuemmeler, Mullins, Van Pelt, Carpentier, & Parkhurst, 2005; Guilfoyle, Denson, Baldassano, & Hommel, 2012; Hullmann, Wolfe-Christensen, Ryan, Fedele, Rambo, Chaney, & Mullins, 2010; Hungerbuehler, Vollrath, & Landolt, 2011; Stoppelbein & Greening, 2007). In these articles, the focus was on stress and family functioning, but each of the articles painted a different picture of the impact of disease related stress. The diseases considered in these articles are: Type 1 Diabetes, Asthma, Cancer, CF, Sickle Cell Disease, Juvenile Rheumatoid Arthritis, and Hemophilia.

Most of the articles that compared diseases concluded there were no easy comparisons of or common conclusions about chronic childhood illnesses or the management of those illnesses. At some points, cancer was noted as causing the greatest distress for parents, but at other points diabetes and cystic fibrosis were singled out as most stressful because of the daily vigilance required to manage the conditions (Carpentier et al., 2008; Fuemmeler et al., 2005; Stoppelbein et al., 2007). The lack of agreement was telling. It showed that parent stress existed in any child health condition and that comparisons or generalizations are unwise. Each disease had its own unique elements and each family functioned differently in the way it coped with disease.

The methods of approaching the disease comparisons in these articles were inconsistent. There was a lack of agreement in terminology and confusion on the impact of disease stress in family units. Some articles focused on Post Traumatic Stress Symptoms (PTSS) (Fuemmeler et al., 2005; Hungerbuehler et al., 2011; Stoppelbein et al., 2007) while others discussed Post Traumatic Stress Disorder (Stoppelbein et al., 2007) and still others investigated Post Traumatic Growth (Hungerbuehler et al., 2011). The terms used to describe stress range from PTSD as a clinical anxiety disorder to PTG, a concept focused on resilience in stressful circumstances. PTSS was the description that was closest to the general distress symptoms being explored in
this research (Fuemmeler et al., 2005). With so many definitions and shades of meaning, however, there was difficulty in knowing for certain how close PTSS, PTSD or PTG are to distress.

The variety of viewpoints in these article indicated the need for further investigation into the coping and stress experiences of parents. Hullmann (2010) saw an increase in stress for parents with a child with diabetes and notes, like Carpentier (2008), that the intricacies of diabetes management may explain a higher likelihood for parenting stress. Hullmann (2010) continued to explain that parents connected to chronic disease management that included a daily care element do not have the opportunity or luxury of succumbing to stress or disease management limiting behaviors. If they do, their children suffer.

All six authors noted that cross-disease comparisons were not an optimal way to review distress for parents (Carpentier et al., 2008; Fuemmeler et al., 2005; Guilfoyle et al., 2012; Hullmann et al., 2010; Hungerbuehler et al., 2011; Stoppelbein, 2007). There were several challenges in these comparisons including differences in: age of children, duration of disease, and disease severity. This lack of commonality and consistency amongst samples made it difficult to match subjects and therefore prohibited continuity across the studies (McClellan and Cohen, 2007). And so, in conclusion, these studies do not tell us much that researchers can reliably use to make conclusions about specific diabetes stress in families. Rather, these articles paint the picture of need across chronic conditions. This part of the review leaves one unsure of the unique aspects of diabetes stress based on the articles that draw disease comparisons.

**Role Strain**

Role strain was another common theme in the literature. Role strain was a situation in which the definition of roles and responsibilities in the family were not clear or well defined.
Recommendations were found throughout the literature for the creation of parent interventions that supported positive coping behaviors and helped reduce fear based parenting, as well as strategies that highlighted the importance of clearly defined diabetes-related tasks for the parents and child (Hegelson, Reynolds, Siminerio, Escobar & Becker, 2008). When there was confusion about responsibilities and a lack of positive diabetes coping behaviors, strain and family conflict often resulted. The division of diabetes related tasks and role definitions were of particular importance in this regard (Hegelson et al., 2008). In this review, five articles specified role strain and the lack of division of diabetes duties (individual responsibility for blood glucose checking, nighttime monitoring of glucose, carbohydrate counting, coordinating medical visits, etc.) as predictors of distress (Hegelson et al., 2008; Haugsvedt et al., 2011; Jaser, 2011; Lewin et al., 2005; Streisand et al., 2005). This was understandable and it was obvious how a lack of shared responsibility can lead to parent stress and potentially diabetes burnout. Parents who take on the most responsibility for diabetes reported the most frequent stress (Streisand et al., 2005). In the Haugsvedt (2011) study, it was shown that the higher the perceived burden related to diabetes treatment tasks (the individual with the largest burden of diabetes management in the family), the higher the level of distress. Therefore, role strain could be considered a cause of distress and pointed toward intervention planning about family diabetes role definitions.

**Parental Expectations**

Parent expectation was another area considered. In this review, parent expectations were revealed through notations about both diabetes control desires and parent concerns about child diabetes management. One study noted that modern recommendations about lower HbA1c levels were potentially linked to greater caregiver stress and fear (Haugstvedt et al., 2010). Cunningham (2011) discussed a relationship between caregiver psychological functioning and
adolescent glucose control. The burden on the caregiver could link to depressive symptoms for the caregiver and to psychological adjustment challenges and diabetes outcomes for the youth (Whittemore et al., 2012). The literature showed that caregiver expectations can correlate to caregiver distress and youth health outcomes.

Another study showed how some parents felt shame when their child’s glucose was out of control (Ginsburg, Howe, Jawad, Buzby, Ayala, Tuttle & Murphy, 2005). The need for control over diabetes, especially in caregivers, was therefore linked to burnout and distress (Lindstrom et al., 2011). Parents tended to expect vigilant attention to diabetes management from their children, yet recognized the overwhelming nature of the condition for their children. It was difficult for parents to set boundaries and diabetes care expectations as their children were maturing. The fear of hypoglycemia was one reason why this was mentioned as so difficult (Haugstvedt et al., 2010). Parents often go to extremes in parenting because of the fear associated with negative diabetes outcomes (Cunningham et al., 2011; Ginsburg et al., 2005). Interestingly, parents were often seen remaining over engaged in diabetes care rather than being supportive of youth independent behaviors. This topic, therefore, suggested another reason for parent distress and fragmented family functioning.

**Theory and Measurement**

It is useful to conclude this literature synthesis with an examination of the use of theory and measurement issues in the articles reviewed. Theory and measurement approaches were assessed in all of the articles in an effort to determine themes and gaps in the literature. Several lessons resulted from this systematic approach.
Theory

The majority of articles reviewed, 40 of 47, were not explicitly guided by theory; however, most articles have an underlying emphasis or acknowledgement of the Life Course theoretical perspective. There was much discussion throughout the literature about the challenge of parenting maturing youth and preparing both caregivers and youth for the transition from dependence to independence. Transfer of responsibility and power were strong elements and are part of the Life Course framework, used dominantly throughout Maternal and Child Health. Social Cognitive Theory was used twice in the 47 articles reviewed, making it the most commonly employed theory (Grey et al., 2011; Monaghan, Hillard, Cogen & Streisand, 2011). Other common themes related to theory included stress theories and an emphasis on understanding family systems (Cunningham et al., 2001; Grey et al., 2011; Lowes et al., 2005; Mellin et al., 2004; Weissberg-Benchell et al., 2009).

The lack of theory underscored a challenge and an opportunity in the diabetes literature. There does not seem to be a strong intersection of public health theory and diabetes clinical research, yet numerous theory-related constructs (self-efficacy, responsibility, division of power, quality of life, coping, etc.) were used in both diabetes clinical and psychological interventions. A stronger connection between these bodies of science would prove beneficial in building an evidence base for study design, as well as intervention development and testing.

Measurement

Numerous measures were used in this review. The measures all emphasized stress, family functioning, and diabetes management. The majority of the studies included questionnaires as a part of the study design (38 of 47). In the questionnaires, the most common measures used were: The Center for Epidemiologic Studies Depression Scale (n=9), State-Trait
Anxiety Inventory (n=7), Pediatric Inventory for Parents (n=7), and Diabetes Responsibility and Conflict Scale (n=5). As expected, HbA1c (n=16), the average indicator of glucose control, was the most commonly used diabetes measure across these studies. The HbA1c clinical measure provided context regarding glucose control.

There were measurement and comparison challenges throughout the articles in this review. The variability in sample sizes and audiences were two such challenges. Samples ranged from 19-425 participants and audiences varied from parents, to youth with disease, and gender specifics parent and child groups. These differences posed challenges in comparing data. This was a significant issue in the literature on this topic. Much work has been done on stress and diabetes, but there was a lack of agreement on how to best measure stress and thus the literature cannot be considered as effective or helpful as one would hope. Creating standardized stress measures would greatly benefit the field.

**Rationale for Research**

Very few articles in this review focused on specific parent interventions for reducing or mediating parent distress and very few articles used common means of assessing parent distress. Most studies discussed how to improve diabetes outcomes. The majority of articles reviewed noted there was need for greater self-efficacy training and better perception of the vulnerability of parents in the clinical setting. Streisand (2008) recommended health educators consider self-efficacy assessments after diabetes education to gauge parent fear and overall acceptance. If assessments become the norm, it may be useful to consider tools that gauge hope and track strategies for coping.

Mednick (2007) wrote about hope as a strategy for ameliorating distress in the family. In the 2007 study, mothers who had high levels of hope tended to have lower levels of anxiety. In
In this study, hope was discussed as an element that makes it easier for individuals to engage in goal setting; it was a motivational framework that allowed individuals to engage a sense of energy to address challenging situations. The result of hope tended to be higher adaption and coping abilities (Mednick et al., 2007). This was a powerful concept to consider when evaluating how to best service families learning to live with diabetes. Perhaps the hope found in the belief of the possibility of a long life with diabetes could alleviate distress.

Schmidt (2012) concluded that reassuring language was a mechanism that can help both parents and children through the disease coping process. Health professionals and parents should both take note of research associated with communication techniques that could improve family relationships. Collaborative, non-judgmental environments and relationships hold promise for helping shape family attitudes related to life with diabetes (Mednick, Cogen, Henderson, Rohrbeck, Kitessa & Streisand, 2007; Schmidt, Chiappetta, Carroll & Beland, 2012).

While the literature review did not reveal many studies on parent distress that were theory driven, the social ecological framework was seen as appropriate for structuring both future research and the ultimate design of interventions. Social Cognitive Theory also was useful to consider because of the many constructs within the theory that relate to family functioning and coping. Therefore, the next section will focus on descriptions of these theoretical approaches and how they apply to the topic of parent distress in diabetes.

Theoretical Approach

The Social Ecological Model and the Social Cognitive Theory have helped to guide this research. The Social Ecological model was used as an overarching framework in this research, as the emphasis in this research was on the interaction of family and individuals with disease.
Social Cognitive Theory was used to explain elements of parent distress as it related to life with disease. Two theories were used here because complete assessment and eventual implementation of a concept requires a mastery of and the use of multiple theories. No one theory is appropriate for all members of an audience. Although this research did not attempt to test either theory, these two frameworks complemented each other to provide for a deeper understanding of the topic of parent distress.

**Social Ecological Model**

The social ecological model builds a picture of the family experience with disease. Ecological models focus on the interactions throughout the experience of disease with special consideration of the multiple levels of influence that impact individuals (Glanz, Rimer & Viswanath, 2008). This framework for understanding then sets the stage for more detailed research and intervention planning in the context of the human experience. The social ecological perspective guided this study for that very reason. It is unrealistic to consider or design research or interventions in chronic disease without fully accounting for and understanding the layers of impact and influence surrounding the person with disease. This theoretical perspective is intended to help researchers segment audiences and consider the internal and external influences on the audiences of interest.

At the core of the social ecological approach is an understanding of individual determinants of behavior, or attitudes, knowledge, and beliefs. The social ecological model considers the totality of the human life and the human social experience. It is understood through the design of the graphic (Figure 1) and the broad use of the model that in all interventions the core individual’s attitudes and beliefs must be considered. In terms of the topic of parents, it is important to recognize how their place in the spheres of influence is impacted by
core beliefs and how their beliefs about their loved one’s disease impacts both their abilities to care for and their loved ones’ ability to cope with disease. This begins to paint the picture of a beautifully complicated scenario.

There are five core levels of influence within this theoretical perspective: Intrapersonal, Interpersonal, Organizational, Community and Public Policy (Glanz et al., 2008). The transactional focus of human development, relationships, and environment are key concepts in this research. As with other research on social ecology, it is thought here that healthy behaviors will be maximized when social environments and influences are considered (Glanz et al., 2008; Ottawa Charter for Health Promotion, 1986). The vast adaptability of the social ecological model is appealing because it allows great flexibility in understanding and interpretation (Glanz et al., 2008).

This ecological perspective is new to diabetes on a clinical level. The convergence of public health and clinical endocrinology has not yet taken hold. It is hoped that lessons from the social ecological framework in this research will form clinical practice recommendations that will benefit both parents and individuals with diabetes. With physical exercise and nutrition, we know that social influences play a significant role in adaption of clinical or behavior change recommendations (Sallis, 2006). Similarly in tobacco cessation, family behaviors are predictors of individual behavior (CDC, 1994). It is proven that multi-level approaches to chronic health
challenges are efficacious. The diabetes literature shows precedent for the use of this model as a guide. The Robert Wood Johnson Foundation’s Diabetes Initiative focused on the interaction of environments and community interventions within the context of the social ecological model (http://www.diabetesinitiative.org; Glanz et al., 2008). Quality of life, clinical outcomes, and engagement of care were all traced back to multiple levels of influence in the social ecological model.

**Social Cognitive Theory**

Social Cognitive Theory (SCT), a widely used theory, is grounded in the assumption that people’s actions are not based solely on objective reality, but on their perspectives of it (Glanz et al., 2008). This is also often referred to as a social learning theory, where meaning is based on social learning within the experience of human behavior. With that in mind, let us consider the influence parents’ perspectives have on a child’s physical and social environments. There is a “dynamic interplay” at work in SCT that positions human behavior with environmental influence (Bandura, 1989). There are three scenarios to consider that are all appropriate for this project: Person to Behavior, Behavior to Environment, and Environment to Person. This theory seeks to explain the changes that occur throughout the course of life (Bandura, 1989). The person to behavior interplay is the most appropriate for this study as it is reciprocal causation that involves the formation of expectations, beliefs, self-perception, goals, and intentions.

*Figure 2: Social Cognitive Theory* (http://www.innovativerlearning.com/educational_psychology/images/recip_causation.jpg).
(Bandura, 1989). All of these interactions affect how people live and ultimately cope with their life experiences.

The interplay between the environment and the person focuses on how social experiences play a role in the formation of social behaviors, as well as some elements of self-perceptions related to abilities, beliefs, and beliefs about life realities. In diabetes, social experiences like diabetes camps and family conferences are major contributors to feelings of strength and efficacy in the life of a person with diabetes and their caregivers. Although different people evoke different responses from social experiences surrounding disease, consideration of the environment within which the behavior takes place is still important to understanding family functioning in life with diabetes (Glanz et al., 2008).

The interplay between behavior and environment is also delicate and revealing. The reciprocal nature of behavior as an effector of the person is also worth note. Here we concentrate on the notion that behaviors and environment are not fixed, they are constantly in flux. Therefore, people are both products of and producers of their environments (Bandura, 1989). This is precisely why SCT is important to consider when investigating families. The opportunity to help families create healthy and helping environments is enormous. The reciprocal notions in SCT are why this theory is so relevant to families grappling with diabetes. For instance, application of the broad concepts in SCT to the diabetes family experience provides much evidence of need. Family camps are a great example. Diabetes family camps put families in a comfortable environment where they can share behavioral challenges related to diabetes and discuss strategies that have worked in other families to improve the overall family dynamic. At these events, observers often see a transformation in parents because they are able to release stress and connect with others who understand and can relate to their situation. This interpersonal level
theory allows for understanding of the environment and the social experience related to the behavior of concern and contributes understanding of the outcomes that result.

Within SCT, there are five categories of constructs: psychological determinants of behavior, observational learning, environmental determinants of behavior, self-regulation, and moral disengagement (Glanz et al., 2008). Within the SCT constructs, particular attention in this research will be paid to environment/observational learning, collective efficacy, self-efficacy, and self-regulation. Parallels will be drawn between some of these SCT categories, parenting styles, and how these relate to the parenting and the success of youth with diabetes.

As we examine elements that are associated with distress, we will do so through a life course mindset. Understanding the growth of the child, family functioning, and distress are important. Expectations, for instance, shift as maturity grows. In early youth, the parental expectations of the child and their participation in care are quite different from adolescence. Similarly, expectations related to family functioning change with time. Division of responsibility is another element that changes dramatically as one moves through the life course. These are all present opportunities for the application of theoretical constructs to research that will investigate and ultimately serve families.

Collective efficacy and self-efficacy look at the importance of beliefs about individual and group ability. Here, this relates to beliefs about the overall ability to manage a chronic health condition, both in the parents and in the overall family unit. This emphasis on belief is a dominant aspect of SCT and for which the theory is well known (Glanz et al., 2008). There is great importance in how a person operationalizes both skill and hope. What a person believes about his or her capacity to cope, as well as his or her attitude about life with disease are important influencers of health outcomes. Just like the famous Henry Ford quote, (“If you think
you can do a thing or think you can’t do a thing, you’re right”), if families believe they can handle diabetes, they are more likely to succeed, while if they believe they will eventually fail, they will do just that. Consistent with Bandura’s foundational work with SCT, in this context self-efficacy beliefs are linked to the ability to change behavior (Glanz et al., 2008).

Self-regulation focuses on the “human capacity to endure short-term negative outcomes in anticipation of important long-term positive outcomes or to discount the immediate costs of behaviors that lead to a more distant goal” (Glanz et al., 2008, p. 174). Self-regulation is about self-control and the acquisition of skills to manage situations. Glanz notes that the basic theme is that individuals can influence their own behavior by organizing environments (Glanz et al., 2008). Rewards are also important in this framework. Much of the operationalization of self-regulation comes in the form of self-instruction and self-monitoring. This is also where social support appears and shows great importance, according to Bandura (Bandura, 1997). The lack of self-regulation, in this research, can be seen as a potential distress predictor and can point to parent emotional need, as well as parenting style.

![Figure 3: Theoretical Logic Model](image)

*Figure 3: Theoretical Logic Model*
The logic model in Figure 3 shows the integration of the Social Ecological Model (categories of Parents and Youth to represent inter- and intrapersonal groups) and the Social Cognitive Theory (constructs utilized in analysis of parent responses). On the left side SCT theory constructs are applied to parents, on the right you can see how parents are nested within the second category of the social ecological approach. This figure is meant to describe and show graphically the importance of parent well-being and how that relates to youth diabetes outcomes. If the parents are not doing well, the youth are at greater risk for poor quality of life and diabetes outcomes. In this research, the youth will only be referenced in terms of the downstream linkage in diabetes and quality of life outcomes.

**Challenges with a Multiple Theory Approach**

The challenge with using these theories is the complexity it creates in analysis. In this study, the Social Ecological Model was used as a framework of understanding the multiple levels of influence within this topic. This model sets the tenor of the exploration. Its design underpins the thought that considering the influencer’s in the life of a person with disease is important and worthwhile. This model doesn’t explain behavior, however it is a valuable guide in segmenting audiences and environments to understand relationships (Stokols, 1996). That will continue to be the primary use of the model here.

My intent in using SCT as a guide in the qualitative portion of the study is to allow SCT to assist in the examination of the constructs of outcome expectations, collective efficacy, self-efficacy, and self-regulation. This is not an effort to explicitly tie the research to theory, but rather to allow the theory to add understanding and context to the information already gathered. Another interest in considering SCT with this research is the emphasis placed on environment
and its link to behavior. The consideration of environment will aid in framing information gathered in the qualitative research specifically to better understand parent feelings and thoughts on social support and coping.

A drawback in using SCT is that this theory tends to focus heavily on negative aspects of behaviors and it then tends to minimize emotional responses. Another limitation is the challenge of considering the maturation process of the person and family. The analysis will highlight SCT’s focus on the interplay of environment and behavior and how families often create environments in which diabetes care is either advanced or thwarted.

It should be noted that the survey instrument used to collect the quantitative information used in this research was not designed with SCT or SEC as theoretical frameworks. Therefore, this study will not be testing theory with this project, but using theory as a guide as this is an applied and exploratory research project (Goodson, 2010).
CHAPTER THREE
Research Methods

Research Design

Purpose

Parents of youth with diabetes experience varying levels of distress throughout the life course with diabetes. Parent distress is largely unrecognized and in most cases untreated. By identifying the type of distress parents are under and the characteristics of parents who experience the most distress, professionals (public health and clinical) can be positioned to better serve families and therefore influence outcomes for the child with diabetes.

This research employed a mixed method, sequential design in which the qualitative component informed the quantitative component. The qualitative section focused on the experiences, needs, desires, and feelings of parents of youth with diabetes as told to the researcher through interview and focus group interactions: the interpretivist perspective of research (Ulin et al, 2005). This aspect of the investigation allowed for a deep understanding of the first hand experiences of parents through their expressions, their spoken words, the discussion of emotions, and their strategies for coping.

The quantitative component used a secondary data set of 332 responses to a battery of questionnaires used to validate the Parent Diabetes Distress Scale (PDDS). Statistical associations were determined between independent variables of interest (i.e., parent self-efficacy, parent emotional support, parent disagreement, and parenting style) and the dependent variable of parent distress. Briefly, the quantitative data analysis was conducted in 2 steps. In step one,
bivariate associations were conducted using the Pearson product-moment correlation coefficient. All of the independent variables that were statistically significant and associated with the outcome variable were used to create the model for examining potential factors that impact parent levels of distress through linear regression.

Both data sets were collected as part of a larger study and instrument creation (PDSS). The research initiated both phases of the larger study and played a role in the study development, as well as the data collection for both data sets. The qualitative data in this research was collected by a USF team of researchers (Johnson and Melton) under the USF Bringing Science Home department. The data for the quantitative portion of this study was collected by the Behavioral Diabetes Institute research team (Polonsky and Fisher) using a battery of validated questionnaires. The quantitative data, guided in part by the qualitative data collected by the USF team, led to the creation of a final, smaller Parent Diabetes Distress Scale (used in this research) and an accompanying website that is currently available to parents of teens with diabetes to assess levels of parent distress.

For the purpose of this research, the SCT and SEC frameworks and the research questions guided the analysis of the original qualitative dataset to provide a greater depth in understanding relevant associations in the quantitative data set. Utilizing a mixed methods design allowed an in-depth understanding of parent feelings and experiences, as well as an opportunity to strategize potential clinical solutions that will ultimately benefit the parents and the child with diabetes.

This combination approach also limits many of the weaknesses associated with an isolated, single method design. Here, this project aims for a comprehensive understanding of the topic of parent distress.
Qualitative Research

Sample

Eligibility

The parents were intentionally similar in life experience and on their life course. Inclusion criteria for the qualitative portions of the study included age range of the child (ages 10-25), age of the parent (over 18 years) and duration of type 1 diabetes (living with diabetes for at least 1 year). As noted above, the qualitative research section allowed an age range of 10-25 years for the children with diabetes. The rationale for inclusion of this age span was based on the assumption that the aforementioned age group reflects the prevalence of diabetes in adolescents and emerging adults. However, due to the convenience sampling method employed for this study, there may be imbalance within each subgroup related to both the age range of the parent’s child with diabetes and the type of participants. The qualitative research was conducted in the Tampa Bay region, while the quantitative research was conducted nationwide.

Recruitment

Recruitment for the qualitative portion of the study relied largely on the personal contacts of the researchers, allowing for broad recruitment via email and list serv advertising in the Tampa Bay region. Tampa area non-profit organization relationships (JDRF, ADA) were also relied upon for assistance with recruitment and advertising. These organizations disseminated the IRB approved research flyers (Appendix H) for the focus groups and the pilot survey/battery of questionnaires to their contact lists. JDRF played a particularly helpful role in promoting the research opportunity to their constituency via family support events and in their monthly newsletters.
Social media was also used in recruitment. Facebook was the main mechanism used through the researcher’s personal social networks, as well as the established Facebook pages of the funding bodies: Bringing Science Home and The Patterson Foundation.

Pharmaceutical company recruitment support was also utilized in this research; Johnson and Johnson’s patient advocacy group, Children With Diabetes (CWD), was one such relationship that was utilized to augment the participant pool. The pharmaceutical support was not financial, but rather advertising of the research opportunity to their respected constituents in Florida.

Several clinical facilities also participated in recruitment at the request of the researcher. The USF Diabetes Center, Tampa General Hospital, St. Joseph’s Children’s Hospital, and All Children’s Hospital were also supportive of this research and directed appropriate patients and caregivers to the research events.

Qualitative Research Methods

This qualitative exploratory study received approval from the USF IRB and was registered as PRO00002291 (Appendix D & E) under the faculty direction of Dr. Carol Bryant. Initial research yielded a convenience sampling of 41 parents of children (ages 10-25) with Type 1 diabetes in the Tampa Bay region. Seven focus groups were conducted throughout a three county area (Hillsborough, Pinellas, and Sarasota), and eleven participants were interviewed in person or by telephone.

Of the 36 families represented in this sample, 24 of the children were female and 14 were male. Three of the families have two children who have been diagnosed with diabetes. All of the participants’ children had diabetes for at least one year. The interviews and focus group
discussions concentrated on the topics of parent coping, parent stress, and family functioning. The research team concluded the qualitative investigation with 41 participants because saturation was met. That is, when the interviewees began repeating themes and concerns, the researchers concluded they had adequate topic information.

Some of the benefits of using qualitative research in this study included the personal interaction with families who are experiencing challenges with diabetes (Nicholls, 2011). Their first person stories were rich with information, culture, wisdom, and context. Practically, qualitative research was a beneficial approach because it tends to be economical, the timing can be flexible, it can be quick when necessary, and the research can be conducted in the absence of technology, although many of the benefits also can pose challenges (Debus, 1986).

The challenges associated with the use of qualitative data include the temptation for researchers to rush to conclusions. The information can be very subjective, which sometimes poses challenges with generalizability (Ulin et al, 2005). Different people can view the same data in different ways so subjective bias tends to be a common limitation in this form of research as well (Ulin et al, 2005). It can also be difficult to verify the data. Researchers tend to struggle with a disciplined approach to qualitative research because of many of these challenges (Debus, 1986).

In an overarching sense, the guidelines related to qualitative research and analysis are flexible, and there is no universal format, so researchers are often improvising which can pose challenges (Debus, 1986; Ulin et al, 2005). The delicate balances in the analysis and interpretation of qualitative research were among the most challenging aspects and the most significant limitations to this research design.
In this study, the focus was on applied, interpretivist qualitative research. The research questions guided the exploration, while the semi-structured nature of the research allowed for flexibility (Maxwell, 2005). Driven by the Social Ecological Model and Social Cognitive Theory, the qualitative portion of this research examined personal experiences, family experiences, aspects of youth and caregiver behavior, and environment. As these elements guided the research, the theoretical approach helped contextualize problems and gaps in services (Ulin et al, 2005).

As noted above, the preliminary results from the qualitative research contributed to the design of the ultimate PDDS tool. The dataset for this research was intended to motivate action in both caregivers and health professionals. It is hoped that the results will help researchers have a clearer understanding of the unique diabetes-related stresses that many parents experience.

The questions used in the focus groups and interviews are located in Appendix F. All of the queries started in story form. Each session began by asking parents to recount their diagnosis experience and feelings to set a common tone. This technique signaled to the participants the value of group interaction and how in the focus group atmosphere, they were amongst friends – they were not alone (Ulin et al, 2005). After all the participants had shared, the interviewers then began to probe deeper into coping strategies, parent needs, gaps in medical care, and then concluded each session by asking parents to “create or imagine” their ideal diabetes clinical experience. The focus group and interview questions followed the “Levels of Interview Questions in a Qualitative Study” as noted in the Ulin textbook, Qualitative Methods in Public Health (p. 83).
Each focus group was recorded with both a computer and a digital recorder. This prevented operator error in recording. Transcriptions were then done with the best recording, typically the iMac computer recording through the software Garage Band.

In each research setting, participants first read and reviewed the Informed Consent document with the research team. Once signatures were collected, the interview/focus groups began.

**Data Management**

The focus group data were transcribed, cleaned of identifiers, and coded by hand. The data were then loaded into *Atlas* for deeper analysis and coding. This software proved to be valuable in assigning the final codes, categorizing data, and aiding the researcher in detailed analysis. All printed transcripts were kept in a locked file drawer and all audio recordings were destroyed once the focus group data was transcribed. Only personnel working with the study have access to the computer and file cabinets. Informed consent forms were also stored in a locked file cabinet to protect participant privacy. The USF IRB required this management of data and security for the research participants.

**Qualitative Data Analysis**

The codebook for the qualitative data can be found in Appendix G. A portion of this instrument was prepared early in the interview process to enable an iterative approach. This approach allowed the researcher to identify consistent patterns (positive and negative) throughout the initial transcription and preliminary analysis. Qualitative research does have a fluid element, so as the research proceeded, some changes were made to the codebook, making it necessary to recode the transcripts previously analyzed.
The formal analysis of the interviews began with an examination of the researchers field notes focusing on reflective observations about body language, environment, and things not said (Bryant, Class Notes, 2010; Ulin et al, 2005). These notes included comments about emotion and visible distress (i.e., crying or partner consoling) and were coded according to the codebook. This information was set aside as the coding process evolved to a deeper level with the transcripts. The researcher returned to the field notes after the first phase of coding was complete to incorporate themes into categories for a more complete analysis.

The second step in the qualitative analysis was paper and pencil coding and an expansion of the codebook. Throughout this coding process, the researcher looked for the most common themes in the data as a way of verifying parent concerns, patterns of communication, and the efficacy of the question script. This point in the coding process allowed for segmenting and categorizing of the data to draw appropriate preliminary conclusions. The a priori or original codes utilized include: emotional distress/psychological needs, material needs, knowledge/people needs, and obstacles/challenges. The codebook was revised continuously throughout the analysis process to reflect accurately the information from parents and to allow for emergent themes.

After a complete look at all of the transcripts and field notes, the information was then imported into Atlas ti software to further categorize, sort, and understand the data. In this axial coding phase, emphasis was placed on the relationships between themes and the interactions in the data set (Ulin et al, 2005; Bryant, Class Notes, 2010). During this phase, subcategories in the codebook emerged and the coding process evolved to its final stage. For instance, at this time themes of distress began to converge with themes of frustration and fear.
Table 1 (below) describes how the qualitative approach matches with the research questions, as well as SCT theoretical constructs. This visual layout of the questioning lines aided in final analysis and assignment of theory to the project results. Many focus group questions are repeated in the table below to show their relevance in multiple social ecological categories and their relevance to multiple research questions for this project. During the final phases of analysis, theoretical constructs were tied to this project more explicitly than they were at the time of project origination.

**Table 1: Qualitative Research Questions and Focus Group Questions**

<table>
<thead>
<tr>
<th>Qualitative Research Question</th>
<th>Social Ecological Level</th>
<th>Qualitative Interview/ Focus Group Questions</th>
<th>SCT Theoretical Constructs</th>
</tr>
</thead>
</table>
| What are parent needs (met and unmet) when raising a child with diabetes? | Intrapersonal Level | • How has diabetes affected your life as a parent?  
• What are some of the greatest challenges you face living with diabetes?  
• What worries you the most?  
• Do you feel your needs as a parent have been acknowledged and addressed by your diabetes health care team?  
• What do you typically do in helping your child manage diabetes?  
• Do you feel there is distress in your family related to diabetes?  
• Where is the distress coming from?  
• Where do you go for help? | • Self Efficacy  
• Self Regulation  
• Psychological Factors |
| What challenges do parents face in life with diabetes? | Interpersonal Level | • How has diabetes affected your life as a parent?  
• Do you feel your needs as a parent have been acknowledged and addressed by your diabetes health care team?  
• Where do you go for help?  
• What advice would you give parents about how to cope with having a child with diabetes? | • Self Efficacy  
• Self Regulation  
• Observational Learning/ Environmental Factors |
Table 1: Qualitative Research Questions and Focus Group Questions (continued)

<table>
<thead>
<tr>
<th>QUALITATIVE RESEARCH QUESTION</th>
<th>SOCIAL ECOLOGICAL LEVEL</th>
<th>QUALITATIVE INTERVIEW/ FOCUS GROUP QUESTIONS</th>
<th>• SCT THEORETICAL CONSTRUCTS</th>
</tr>
</thead>
</table>
| What strategies are most helpful for parents working to help manage their child’s diabetes? | Interpersonal Level | • Where do you go for help?  
• What advice would you give parents about how to cope with having a child with diabetes?  
• Where would you refer a friend for medical help or support?  
• If you could design a program for parents like you…what could this program do to help? | • Self Efficacy  
• Self Regulation  
• Observational Learning / Environmental Factors  
• Collective Efficacy |

The final data analysis was augmented by quotes and ideas from parents to keep their voice alive in the research. This phase of analysis moved beyond descriptive information and delved into the meaning behind parent personal experiences and the stories parents shared. This was where triangulation of the qualitative and quantitative data occurred.

Quantitative Research

Sample

Eligibility

Inclusion criteria differed slightly for the quantitative portion of the study. The difference was in the age range of the child of the parents. The quantitative research section allowed a smaller age range (11-21) for participants than the qualitative section. This was to specifically target parents of teenage youth with diabetes or those with recent teenage experiences.
Recruitment

A convenience sampling method was used for recruitment purposes. The deep social capital of the researchers involved (Johnson and Polonsky) allowed for broad national recruitment via email and list-serv advertising. National non-profit organization relationships (JDRF, ADA) were also relied upon for recruitment and advertising.

Social media was utilized in survey recruitment. Facebook was the main mechanism used through the social network of the researchers, as well as the established Facebook pages of the funding bodies: Bringing Science Home and The Patterson Foundation and targeted Facebook group advertising. The researchers also engaged pharmaceutical company support for the research. Johnson and Johnson’s patient advocacy group, Children With Diabetes (CWD), was the primary relationship utilized to augment the participant pool. This organization focuses heavily on the target audience and played a significant role in the creation of the sample. Specifically, CWD used their email lists to message their constituency about the opportunity to participate in the study. CWD also included the research opportunity in their weekly newsletter for several weeks prior to the closure of the study. It is important to note that the pharmaceutical company support was not financial, but rather provided advertising of the research opportunity to their respected constituencies.

Several clinical facilities also participated in research recruitment at the request of the primary researcher (Polonsky).
**Quantitative Research Methods**

The inclusion of quantitative data in this research project allowed for a more explicit assessment of parent characteristics, parent feelings, and parenting styles through the examination of the related statistics, frequencies, and correlations.

The focus of the quantitative analysis in this research was on descriptive statistics, correlations, and multiple regression. The aim was to assess the association between parenting styles (authoritarian, authoritative, and permissive), parent self-efficacy, parent emotional support, and parent disagreement with distress. This allowed for a better understanding of the factors that might be linked to distress in parents.

**Data Sources**

The data set (secondary data) utilized in this study was from the large multi-questionnaire battery used to validate the Parent Diabetes Distress Scale (PDDS). This questionnaire battery received IRB approval (Appendix I) from Ethical & Independent Review Services (E&I ID 12172). This approval was sought by the research team of Dr. Bill Polonsky and Dr. Larry Fisher at the Behavioral Diabetes Institute in San Diego, CA. The questionnaire battery, developed by the Behavioral Diabetes Institute, included a series of questionnaires aimed at gathering data to understand the variance in parent distress according to a number of variables.

**Variables**

To fully discuss the variables in the quantitative research, we must return to the research questions:

- What is the relationship between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?
• To what degree, if at all, is parent self-efficacy associated with diabetes-related distress?
• To what degree, if at all, is emotional support associated with diabetes-related distress?
• To what degree, if at all, is parent disagreement associated with diabetes-related distress?
• To what degree, if at all, is parenting style associated with diabetes-related distress?

The dependent variable of distress considered is specifically diabetes-related distress. This differs from general life stress or general distress, because it emphasizes the complexity of and the challenges associated with the daily management of diabetes.

Measurement

Of the questions in the large questionnaire battery (Appendix J), 4 individual questionnaires were selected for investigation with this research. The dependent variable used in this research was parent distress. This variable was identified in the Parent Diabetes Distress Scale (Table 2). Table 2 illustrates the 20 questions and the four domains that categorize distress (i.e., Distress about my relationship with my teen, Distress about myself, Distress about my teen, and Distress about my teen’s medical care). The PDDS data indicated the parent/teen relationship as the most common source of distress. The proposed research was aimed at assessing the impact of parent self-efficacy, parent emotional support, parent disagreement, and parenting style on distress, as well as how it could help us better understand the parent/teen relationship. The goal was to understand more clearly why parents are distressed.
Table 2: Parent Diabetes Distress Scale (PDDS)

<table>
<thead>
<tr>
<th>Feeling that my teen and I just don’t work well together when it comes to diabetes</th>
<th>Relationship with Teen</th>
<th>Self</th>
<th>Teen</th>
<th>Healthcare Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling that I can’t trust my teen to take good care of his/her diabetes</td>
<td>.935</td>
<td>.070</td>
<td>.014</td>
<td>.035</td>
</tr>
<tr>
<td>Worrying that my teen will ignore or forget diabetes if I don’t keep reminding him/her</td>
<td>.761</td>
<td>.089</td>
<td>.136</td>
<td>.036</td>
</tr>
<tr>
<td>Feeling that trying to help my teen with his/her diabetes is always a battle</td>
<td>.870</td>
<td>.084</td>
<td>.021</td>
<td>.013</td>
</tr>
<tr>
<td>Feeling that my teen doesn’t do enough to manage his/her diabetes</td>
<td>.981</td>
<td>.088</td>
<td>.047</td>
<td>.020</td>
</tr>
<tr>
<td>Frustrated because my teen ignores my suggestions about diabetes</td>
<td>.851</td>
<td>.071</td>
<td>.032</td>
<td>.032</td>
</tr>
<tr>
<td>Uncertain about how to motivate my teen to take better care of his/her diabetes</td>
<td>.878</td>
<td>.053</td>
<td>.007</td>
<td>.011</td>
</tr>
<tr>
<td>Worrying that my nagging about diabetes is hurting my relationship with my teen</td>
<td>.658</td>
<td>.224</td>
<td>.101</td>
<td>.005</td>
</tr>
<tr>
<td>Feeling unappreciated for all the ways I try to help my teen manage diabetes</td>
<td>.344</td>
<td>.601</td>
<td>.037</td>
<td>.041</td>
</tr>
<tr>
<td>Feeling diabetes is taking up too much of my mental and physical energy every day</td>
<td>.059</td>
<td>.657</td>
<td>.177</td>
<td>.044</td>
</tr>
<tr>
<td>Feeling that no one notices that diabetes is hard on me, not just on my teen</td>
<td>-.095</td>
<td>.931</td>
<td>.017</td>
<td>.045</td>
</tr>
<tr>
<td>Worrying that others will blame me if my teen’s diabetes is not well-controlled</td>
<td>.317</td>
<td>.568</td>
<td>.108</td>
<td>.006</td>
</tr>
<tr>
<td>Frustrated by the lack of understanding and support for diabetes I get from friends and family members</td>
<td>-.033</td>
<td>.774</td>
<td>.070</td>
<td>.095</td>
</tr>
<tr>
<td>Frustrated that I am the only one who takes responsibility for helping my teen manage diabetes</td>
<td>.288</td>
<td>.605</td>
<td>-.066</td>
<td>.028</td>
</tr>
<tr>
<td>Worrying about my teen’s low blood sugar when he/she is away from home</td>
<td>-.031</td>
<td>.061</td>
<td>.839</td>
<td>-.005</td>
</tr>
<tr>
<td>Worrying that my teen will soon leave home and I cannot protect him</td>
<td>.321</td>
<td>-.101</td>
<td>.660</td>
<td>-.008</td>
</tr>
<tr>
<td>Worrying about my teen’s low blood sugar when he/she is sleeping</td>
<td>-.206</td>
<td>.172</td>
<td>.817</td>
<td>-.029</td>
</tr>
<tr>
<td>Concerned my teen is not prepared to deal with the world of insurance &amp; doctors once he/she is an adult</td>
<td>.360</td>
<td>-.157</td>
<td>.512</td>
<td>.063</td>
</tr>
<tr>
<td>Worrying that my teen doesn’t get all of the expert medical help he/she needs</td>
<td>.008</td>
<td>-.022</td>
<td>-.007</td>
<td>.942</td>
</tr>
<tr>
<td>Worrying that my teen doesn’t get all of the expert medical help he/she needs</td>
<td>-.011</td>
<td>.041</td>
<td>.004</td>
<td>.917</td>
</tr>
</tbody>
</table>

(Hessler, D., Polonsky, W., Fisher, L. and Johnson, N., 2012)

The specific questions to be examined from the questionnaires are summarized in Table 3. All of these questions are relevant to the aims of this study and were used to answer the research questions set forth.

The internal validity of the entire battery of questionnaires was previously established through the use of Cronbach’s alpha and cited in a conference presentation on the preliminary report from this data set by the Behavioral Diabetes Institute (Hessler et al, 2012).

Independent variables considered from the questionnaires included parent self-efficacy, parent emotional support, parent disagreement, and parenting style. The original data collection was designed to examine numerous variables related to distress, yet not all of those original variables from the master data set were considered in this research.
The analysis included looking at the correlations between each of the variables of interest. All variables found to be statistically significant were included in the final predictive model. Throughout the analysis, age, gender, and duration of diabetes were included as control variables.

Figure 4 shows graphically the correlations to be considered. Distress in this figure remains the constant comparative element. Under Parenting Styles, the three styles of interest are noted. (A fourth parenting style, neglecting, is not included in this assessment.) There are no arrows showing influence from the Parenting Style category to the type of parenting, as to represent the different styles are parts of the overall Parenting Style construct. Each parenting style was considered separately in the analysis of the data set, and then conclusions were made about the importance of parenting style generally in the discussion section of this research.

Table 3: Variables Matched with Questionnaire Items

<table>
<thead>
<tr>
<th>Variable</th>
<th>Research Question</th>
<th>Items in Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Efficacy</td>
<td>What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?</td>
<td>During the last month how confident have you been about: (n = 332)</td>
</tr>
<tr>
<td></td>
<td>To what degree, if at all, is parent self-efficacy associated with diabetes-related distress?</td>
<td>1. Your overall knowledge about diabetes. (1-4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Your ability to manage your teen’s diabetes. (1-4)</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?</td>
<td>Over the past month, how much emotional support have you personally received from others regarding your coping with diabetes and your teen? (n = 332)</td>
</tr>
<tr>
<td></td>
<td>To what degree, if at all, is emotional support associated with diabetes-related distress?</td>
<td>1. From friends and family members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. From health care professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. From other parents who have teens with diabetes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. From support groups, live or online</td>
</tr>
</tbody>
</table>
Table 3: Variables Matched with Questionnaire Items (continued)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Research Question</th>
<th>Items in Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenting Style: Authoritative</td>
<td>What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?</td>
<td>For each statement, please circle the number that describes your beliefs about parenting your child. There are no right or wrong answers. (n = 332)</td>
</tr>
<tr>
<td></td>
<td>To what degree, if at all is parenting style associated with diabetes-related distress?</td>
<td>1. When I ask my teen to do something, I expect it to be done immediately without questions.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. I do not allow my teen to question the decisions that I make.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. I get very upset if my teen tries to disagree with me.</td>
</tr>
<tr>
<td>Parenting Style: Authoritarian</td>
<td>What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?</td>
<td>For each statement, please circle the number that describes your beliefs about parenting your child. There are no right or wrong answers. (n = 332)</td>
</tr>
<tr>
<td></td>
<td>To what degree, if at all, is parenting style associated with diabetes-related distress?</td>
<td>1. I tell my teen what he/she should do, but I explain why I want them to do it.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. I expect my teen to follow my directions, but I am always willing to listen to their concerns and discuss the rules with them.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. If I make a decision that hurts my teen, I am willing to admit that I made a mistake.</td>
</tr>
</tbody>
</table>
Table 3: Variables Matched with Questionnaire Items (continued)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Research Question</th>
<th>Items in Questionnaire</th>
</tr>
</thead>
</table>
| Parenting Style:        | What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?  
                         | To what degree, if at all, is parenting style associated with diabetes-related distress?                                                                                                                                  | For each statement, please circle the number that describes your beliefs about parenting your child. There are no right or wrong answers. (n = 332)  
                                                                              | 1. My teen needs to be free to make his/her own decision, even if this disagrees with what I might want to do.  
                                                                              | 2. Most of the time I do what my teen wants when making decisions.  
                                                                              | 3. Most problems in society would be solved if parents would let their teens choose their activities, make their own decisions and follow their own desires when growing up. |
| Permissive              |                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                       |

Figure 4: Distress Variables


**Data Refinement**

Once the questionnaire data was thoroughly examined, decisions were made about cleaning the data for specific question-driven data analysis. Data sections not relevant to this study were removed from the data set and a specific file with 10 variables was crafted from the original data set of 185 variables. The variables in the data file included demographic variables (i.e., age of parent, gender of parent, duration of diabetes of child), distress, self-efficacy, emotional strain, parent disagreement, and parenting style variables.

During the cleaning process, variable names were changed for consistency and easy identification. The researcher also made sure to identify variables that related to the parent versus variables related to the youth.

**Quantitative Data Analysis Plan**

The model in Figure 4 examines the relationships between parenting styles and distress. There were many correlations to look at in this model and those correlations were used to answer the research questions proposed (Table 4).

Whether a linear relationship exists between the dependent variable of distress and independent variables of parent emotional support, parent disagreement parent self-efficacy and parenting style were first assessed graphically pairwise using a two-way scatterplot. One-tailed Pearson correlation tests were used to examine the association of, self-efficacy, emotional support, parent disagreement, and parenting style with parents’ distress. Pearson correlation coefficients were also used in the specific assessment of the association between distress and parenting style (authoritative, authoritarian, permissive). It is important to note that the correlation coefficient merely tells us that a linear relationship exists between two variables; it
does not specify whether the relationship is cause and effect. All independent variables found to be significantly correlated with parent distress were used to construct a multiple regression model while controlling for confounders (e.g., parents’ age, gender, etc.).

To construct the multiple regression model and find the best regression equation, the researchers used the all possible models approach, emphasizing backward stepwise elimination. In the backward elimination method, all variables are introduced at once and then each variable is dropped. The data was analyzed with SPSS and STATA software.

All of the research questions were addressed with multiple linear regression and correlation equations. The p-value was set at .05 for all analysis and Pearson’s correlations were assessed. For each question the social ecological level considered is the interpersonal level.

**Linking the Data - Triangulation**

When the data were triangulated, findings from both sections of the research augmented each other and showed the strength of the research design. The qualitative section offered insight into the needs of parents and the factors that created challenges for parents. The quantitative section highlighted factors associated with distress. The results and discussion sections included many quotes from parents experiencing distress as the research utilized a narrative approach to focus on relevant themes.
CHAPTER FOUR

Results

The purpose of this study was to explore parent distress in diabetes by identifying the challenges parents face and the factors correlated with high levels of distress. The aim of this study was to understand how public health and clinical professionals can assist parents in coping with their child’s diabetes and living positively as a family unit. The study employed a sequential mixed methods design. This chapter is therefore divided into two parts: qualitative research findings and quantitative research findings.

The main task in the qualitative section was to understand the challenges, needs, and coping strategies used by parents living with a child with diabetes. The quantitative section focused on understanding and identifying factors associated with parent distress with emphasis on the variables of self-efficacy, emotional support, parent disagreement, and parenting style.

Qualitative Research Questions

The qualitative analysis sought to answer the following research questions for this portion of the study:

• What are parent needs (met and unmet) when raising a child with diabetes?
• What challenges do parents face in life with diabetes?
• What strategies are most helpful for parents working to help manage their child’s diabetes?
Data to answer the research questions were obtained through semi-structured individual interviews and focus group discussions. Transcripts were analyzed by the examination of emergent themes through the data analysis software Atlas ti.

Sample Description

The qualitative sample consisted of seven focus groups and ten individual interviews. A total of 41 individuals participated with the majority being female (35 Female / 6 Male). The children with type 1 diabetes represented were between the ages of 10-25. Of the children, 24 were female and 14 were male. Three of the families have more than one child with type 1 diabetes. The participants self-selected to be a part of the qualitative research and thus the sample may not represent the total population of parents with a child living with diabetes.

Qualitative Findings

As these results showed, nothing about raising a child with diabetes is easy for families, and thus, there was a need for this in-depth look at parent stress and coping. After examining parents’ needs and the challenges parents face, this section summarizes the strategies parents have employed to cope with these challenges.

Parent Needs and Challenges

The focus groups and interviews revealed three categories of needs and challenges, as well as numerous issues within each category. (See Appendix G for a list of themes and sub-themes identified.) The three thematic categories are outlined below:

• Community and social stressors refer to challenges parents encounter when navigating institutions, such as educational and health care organizations.
• Interpersonal challenges refer to the stressors that affect parents as they interact with friends, neighbors, and family members.

• Personal issues refer to the emotional stressors parents encounter when raising a child with diabetes.

Taking a social ecological approach, this section starts with distal level or societal stressors and moves to the interpersonal challenges and then to internal stressors.

**Community / Social Stressors**

Parenting a child with diabetes requires the navigation of many societal institutions. Three of these organizations – schools, health care systems, and diabetes organizations -can prove especially difficult and were examined in detail with this sample.

*School Systems*

*Primary Education*

Managing diabetes in the school setting is one of the biggest challenges facing parents. Sending a child with diabetes to an environment that is not necessarily friendly or prepared to cope with the demands of a complex, chronic disease presents a variety of parental challenges.

The most dominant challenge for parents is child safety when at school. Parents’ fears centered on the school personnel’s ability to help their child manage diabetes. They expressed deep concern about the school’s willingness to assist the diabetic child both in emergencies and with everyday tasks. Safety concerns included, but were not limited to, how the child will receive care when experiencing a low blood sugar, where the child will receive this care (classroom or school office), and who will deliver the care.
“My main concern is safety, always safety first. You know no matter where he is that somebody is around him that will know to intervene and help him through his crisis.” - Female, 17-year old son

The availability of an on-site school nurse or other school personnel who understood the nature of the disease was key. As one mother noted, there needs to be someone who “gets it”, and allows the child the flexibility to have snacks or perform glucose monitoring in the classroom.

Parents have had difficulty educating school personnel about their child’s diabetes. Differences between Type 1 and Type 2 diabetes can lead to inappropriate treatment and conflict. For example, a teacher could assume it is safe to tell a child with a low blood sugar to walk alone to the front office for assistance if the teacher is using the context of knowledge about a person with Type 2 diabetes, rather than Type 1 diabetes. Parents also recounted stories of confusion in the school setting as teachers and administrators were not prepared to recognize diabetes technology and tended to mistake insulin pumps for cell phones or other prohibited items.

Many families described positive relationships with teachers, school nurses, and school administration, but several others had experienced challenges because of the lack of flexibility in school systems. Many times, because of regulations and financial strain in school systems, parents were forced to alter their lives to be able to be at the school multiple times each day to test their child’s blood sugar and deliver insulin.

“My school nurse said, ‘You have two options – you have to home school her or you switch her school.’ Those are not options. That is not the right answer!” - Female, 10 year-old daughter
Many schools and school personnel were unable to take on the care giving role or the liability they (school) perceived associated with the monitoring of blood sugar and delivery of insulin. The inefficiency in the system posed multiple challenges for all individuals involved.

“The school calls me constantly to tell me her sugar is 55 and that I need to pick her up and I say, ‘No, give her juice.’ I don’t understand. Everything is there for them. I know they are being over protective, but still you have to have some kind of sense….every day I get calls from the school. It is frustrating. There has got to be a better way. It is embarrassing for her – to constantly go to the office, to constantly pee in a cup, to constantly get tested. She is now embarrassed to raise her hand if she feels sick or low.” – Female, 11 year-old daughter

**Collegiate Education**

Parents also described how developmental transitions during adolescence were magnified when a child with diabetes leaves home to attend college. Although these parents, like others, want their children to become independent and self-sufficient, they struggle with knowing at what point and how much to “let go”. Most parents described their anxiety related to this life stage, and how they feared the moment they must relinquish control over diabetes and trust that their child will self-manage.

“I’m more stressed to get her to be more independent and responsible for her diabetes. I feel like time is running out. I’ve only got two years before she is in college. So, I feel like the clock is running and it’s a constant battle of how much freedom to give...
“her and how much I need to be on her.” – Female, 15 year-old daughter

Respondents reported that as youth mature, it is more difficult for parents to communicate with people working in the collegiate setting, and parents worry about what they can do to ensure their child’s needs are met.

“If there is at least one RA in the dorm that recognizes diabetes that will help me sleep better at night. What is he going to do when they go off to college? Where is my child going to hide the stash of insulin, cookies and hard candy?” – Female, 17 year-old son

Finally, parents were concerned about how their children will navigate a new social environment and raised questions about student health services, participation in Greek organizations, collegiate housing, and food access.

**Legal Issues**

All the parents in this sample who have school-aged children reported having a plan that outlines detailed procedures for daily care and emergencies (called a 504 Plan) in place for their child. These plans are intended to avoid crisis by detailing emergency care plans for low or high blood sugar episodes and outlining ways the child can exhibit personal responsibility for his/her diabetes. At times, these plans have also included information related to extracurricular activities so the child with diabetes is afforded the same opportunities as other children.

Parents felt strongly about ensuring legal protection for their children and spoke firmly about the concerns they have for their child’s rights in the school setting. Many parents explained that they want their child to thrive even though they have diabetes, yet at the same time they also want their child to be understood as a victim of the disease.
One parent spoke at length about the discrimination her daughter had faced because of having diabetes. Her daughter had been the victim of intense bullying. The mother tried to remedy the problem by working with college administrators and the U.S. government (HUD) to properly care for and protect her child’s rights. Results were mixed: while receiving some housing accommodations that have enabled her to complete her program of study, the sorority associated with the bullying was not held accountable or punished and the college has yet to develop a system to prevent this from happening in the future to other students with diabetes.

“It was incredibly difficult. To be called names and be accused of being unsafe because of diabetes...We are so proud of how she handled the situation and that she decided to go back. Although, I would have preferred that she stayed home to finish school.” – Female, 19 year old daughter

This case raises important legal issues that colleges and universities face in meeting the needs of students with diabetes.

*Health Systems*

All of the parents interviewed spoke of challenges they encountered with health systems. The most common problems were understanding medical information, connecting with the right health providers, navigating multiple recommendations, and applying the information learned to real life. These problems appeared to unfold in three phases as parents dealt with the initial diagnosis, sought information about the disease, and then searched for specific solutions.

*Clinical Services*

The diagnosis experience was described by parents as dramatic for families and often filled with extensive frustration. Parents discussed frustration in the context of clinical services.
and care focusing on stories of diagnosis, traumatic diabetes experiences/treatments, and challenges with obtaining the needed disease education. Parents described this clinical frustration in three phases: Diagnosis, Education, and Discovery.

**Figure 5: Clinical Frustration Phases**

**Diagnosis Challenges**

Many parents described the initial diagnosis of Type 1 diabetes as a life-changing crisis. While parents grappled with many emotions, they also described how they were often frustrated by the health care experience. Parents spoke of how they were required to learn a great deal of information on diabetes care and adopt a demanding, new lifestyle that required them to modify all of their family’s daily practices immediately upon diagnosis. Adjustments to new foods, new routines, new requirements about exercise, the daily delivery of insulin, frequent blood sugar checks, and social concerns about diabetes made up the bevy of challenges these parents faced at diagnosis. Many parents learned quickly that these changes are not easy to make, and they were forced to lower their initial expectations for diabetes management perfection. One parent spoke of how her expectations were shattered when, even with a physician in the family, diabetes proved to overwhelm and often overcome them. Parents repeatedly emphasized the need for
clinical support, especially during the early stages of diabetes, as families learn to cope with their new lifestyle and understand the realities of life with disease.

**Health Education Challenges**

Parents reported that most clinical diabetes education was conducted in one or two long informational sessions within weeks of the initial diagnosis. Parents described the difficulty of absorbing the amount of information they needed to successfully manage the disease. They also shared how they wished health professionals could give them more attention and education.

“*We literally were in and out of there in 1 ½ hours and they said ‘we will see you in 2 weeks.’ The diabetes educator told us how to give a shot and we were out of there and they say, ‘we will see you in 2 weeks’ those were the scariest 2 weeks for us.*” – Female, 14 year-old daughter

Parents expressed frustration with the process of obtaining education and then applying the information learned in workable ways. Diabetes education was thus described as overwhelming. Parents spoke of how they yearn for ways to better integrate the extended family into formal diabetes education to aid in application of information and to bolster confidence.

“For me, I think, just more background as to what it [diabetes] is. I know what diabetes is, as far as the physical things that diabetes does to the person, but what exactly is it? And how can I help him in circumstances. Like when he’s low, what kind of foods can I give him to bring his count up? When his blood sugar is too high what can I do to help him? I think maybe he’s the one that has the
"disease, but people like me who are like living with it everyday, need certain information." – Male, 10 year-old son

Other parents spoke about the need for extended engagement with the health team (beyond diagnosis and initial disease education) and how the health system could be better organized to give more complete services, including better family communication and more empathy for caregivers.

“It was hard. I called and cried. The social worker said why are you crying? Why are you so upset? And I said she has this disease and they said don’t think of it as a disease. I thought well, OK we can change the word but it is still the same. It is life altering. It’s going to be there until a cure is found. I guess I feel like I didn’t get a lot of empathy.” – Female, 11 year-old daughter

Parents discussed how they desire reinforcement from the health team for things that have gone right in their management of their child’s life threatening condition. Parents shared about how they felt “beat up” in clinical discussions about the things that go wrong with diabetes. These expressions led parents to talk about how they seek more understanding and collaboration from the health team.

“We can’t always be the bad guys. We need the health team to reinforce us.” – Female, 10 year old daughter

Communication improvements within the health system were a major discussion point for parents. Parents desired more access to the health team, as well as more ways to engage with health professionals about the family dynamics that surround diabetes.
“It would help to have a health care professional who recognizes the key role that the parent plays in making diabetes care decisions and that while it is the health professional who has the expertise about diabetes, the parent has the expertise about the child.” – Female, 13 year old daughter

Parents suggested parent-specific encounters in the health care setting to allow for broader clinical understanding of diabetes realities in the home and the further establishment of a relationship with the entire family. They described how health team encounters with only the child with diabetes did not provide the full context of the family dynamics around diabetes.

Discovery Challenges

More experienced diabetes parents talked about how they have moved beyond their efforts to understand diabetes management and were more focused on scientific discovery and diabetes research. These families expressed concern with the time it is taking to find a cure or better therapies for their children. They also strongly communicated about their interest, frustrations, and concerns about medical research and product development. This is the stage when many parents adopt an advocacy approach to life with diabetes and become active in fundraising for a cure or better treatment.

There was universal agreement among parents in this study that the health system could provide more and better support services for people with diabetes and their families.

“Parents need quicker and easier access to medical professionals. That is something no support group, no mentor program, no JDRF
can do. *Organizations can't do the medical piece.*” – Male, 10 year-old son

**Legal Issues**

Legal issues were also problematic in health systems. As children became older, parent access to information about and inclusion in diabetes care changed. Parents noted that all families were not ready for change at the same point in time. Current laws were designed to protect patients’ privacy, but at the same time they deny parents access to the medical information they may need to help their child. Parents shared their desire to continue active participation in clinical discussions without having to obtain their child’s approval after he or she turns 18 years of age.

**Diabetes Organizations**

Diabetes organizations play a significant role in the lives of families with diabetes. While parents reported they value these organizations, they also expressed dissatisfaction with the narrow breadth of services the organizations provide. Many parents stop participating in diabetes organizations after their children become teens. Parents express disappointment that organizations do not meet the needs of families as they experience the maturation process of the child with diabetes.

Parents stated that they wished diabetes organizations would do more to educate the public about the differences between Types 1 and Type 2 diabetes. Parents lamented the lack of precise information on how diabetes affects a child’s maturation. Parents spoke of the value of self-help parenting guides, such as those designed to help parents when their child learns to drive or leave home for college. They expressed disappointment that comparable guides were not
available to help them with the demands posed by diabetes as children move through the different life stages.

“It is like the’ what to expect when you are expecting’ books where you know that at a certain age the child is in a car seat, and then at a certain age they wear a helmet. There is nothing to tells me what to expect in diabetes.” – Female, 17 year-old daughter

Interpersonal Challenges

Throughout the qualitative research, parents discussed numerous relational challenges that influence their ability to manage and cope with diabetes. Peer and familial support were described as extremely valuable to the parent, however access to such support was described as not always readily available. Parents discussed interpersonal challenges in the context of their quest for support, the judgment they often felt, and the family conflict that is sometimes present in life with diabetes.

Lack of Support

Parents said that they need personal reinforcement (support and affirmation) to augment their ability to emotionally and physically cope with life with diabetes. They talked about the value of support and how difficult it can be to connect with others. Connections to those who understand their challenges and can relate to their experiences were described as essential.

“The best thing is talking to other parents, other kids that know that that is life with diabetes.” – Female, 13 year-old daughter

Those who have benefited from support talked about the transformational nature of community. Relationships with peers who understood the turmoil of the diabetes experience were considered a “gift” in the process of life with a chronic condition.
Despite its value, support was often lacking. Most parents expressed a need for support related to lifestyle issues surrounding diabetes. In these discussions, parents had a difficult time separating their needs for support from their child’s needs. In the midst of speaking about how the parents seek friendships with other parents that are like them, most participants turned the conversation to the need for the child to have support through adolescence too.

**Judgment from Others**

Some parents felt others criticized their care for the child with diabetes. Much of the criticism stemmed from a general lack of understanding about Type 1 diabetes. Parents shared experiences where others had asked them “did you give her [the child] too much sugar?” or “was your child overweight?” The difficulties surrounding the explanatory process of the differences in Type 1 and Type 2 diabetes were repeated often. Parents felt others were judging them when they were asked questions like these about how they have cared for their children.

Parents also explained that they judged themselves when their child’s disease was not managed successfully. The clinical A1c measure was referenced in this regard as the “Good Mommy Award” signifying parent achievement or failure.

**Family Dynamics**

Another challenge parents discussed was family conflict. Participants reported that their marital and family relationships were strained by the challenges of raising a child with diabetes. They frequently experienced problems in negotiating how to share the extra work diabetes creates, as well as in the shared decision making that diabetes requires. The frustrations that accompany life with diabetes often caused parents to express feelings negatively to each other. Most often family conflict was noted in regard to tension in the family unit related to diabetes.
“You go through a tremendous amount of guilt. And there is no
counseling for the parents. You can talk about going to a [support
group], but most people aren’t going to do that...”

“...You go home. You internalize it. You take it out on each other.”

- Male, 11 year-old son

At times parents responded to family conflict in unexpected ways. Most often, mothers
suggested they felt overburdened. One mother, though, spoke of how she wants help from her
spouse, yet she takes on the entire burden of diabetes.

“He is wonderful and we are together, but he has never stepped up
to really help. Once in a blue moon, because he stays up later than
me, he will check her later at night or something, but he basically
knows how to do that. But other than that he is absolutely clueless
and has not taken a role to try to figure it out. My daughter wishes
he would. But at this stage of the game, I feel like it is too late
already.” –Female, 17 year-old daughter

Sibling stress was repeatedly mentioned as another significant familial concern. The
increased attention placed on the child with diabetes impacts the dynamics between siblings.
Parents reported that while siblings are protective and caring, the siblings receive less attention
and sometimes conflict and jealousy results.

Overall, family conflict discussions centralized on the need for normalcy and the
intensity of planning. Diabetes was described as a disruption in the family unit and something
that causes friction in general family relationships.
Personal Issues in Life with Diabetes

Parents described fear as the most significant of their emotional struggles in facing diabetes. Emotion was the driving force in all conversations with parents. At times discussions were purely about the emotion of the situation; at other times emotion was discussed in the context of parent challenge. In many instances throughout the research, there were both physical and verbal displays of emotion.

Fear

The emotional strain associated with diabetes was evident as parents discussed feelings of fear, loss, and sadness. Parents described a sense of loss beginning with the “trauma” of the diagnosis experience and then the grief over the loss of a “normal” family life and childhood for both them and their child. Parents described worrying that diabetes might hold their child back from doing things in life, as well as fear about the influence of diabetes in the child’s relationships throughout life.

The fearfulness parents experienced in managing the life and death condition in their child was augmented with the fear of further health complications should they make a mistake in their care delivery. The life and death tightrope parents walk was described as frightening and unforgiving. The form of caregiving demanded of parents was riddled with self-doubt, driven by the underlying and unrelenting fear. All parents expressed fear related to what is next with diabetes and all felt largely unprepared for their future with diabetes.

Another repeated theme in the discussions around parent fear was the impact of negativity on the family. This topic was discussed from many different angles including negativity about the effects of diabetes to negativity of the parent’s behaviors and actions. Participants described their efforts to avoid horror stories from others, and their desire to avoid
too much focus on information about complications in an effort to protect themselves and their child from information overload and unhealthy fear.

Safety Concerns

Safety was partly about the child staying safe and the creation of safe environments for the child, and partly about parental control. There was also a strong element of fear within safety, yet safety is larger than a specific emotion. To parents, safe environments included readily available access to diabetes supplies, food and drink, and knowledgeable people who were willing to assist with diabetes care. Parents desire “a safety net” of individuals who can help their child in case of an emergency. Therefore, many parents described that a part of their role was to educate people about diabetes in order for their child’s condition to be understood and their child to be safe. In one instance, a parent shared a recollection of a neighborhood experience where the child had a low blood sugar emergency and the neighbors didn’t want to give the child sugar because of diabetes. For this reason, many families preferred their child’s play dates occur at their own home where they can control the environment. Parents reported not allowing their child to attend sleepovers or go to friends’ homes until they were confident that the child can take care of herself and that the other parents were able to handle the child’s needs.

“...because I just don’t trust other people to take care of her.” – Female, 10 year-old daughter

“I think it can be overwhelming for the parents and I think it can then translate to the kids. If the parents don’t feel safe, the kids aren’t going to feel safe.” - Female, 13 year-old daughter
Grief

Grief was reflected as parents talked about their child having to “grow up too soon” and that the child has “accepted such responsibility at a young age.” There was a sadness, a chronic grief as one parent described it, which accompanies this sort of life altering condition.

“Now I feel like I lost his childhood. I’ve taken on the role of caring for him so I still want him to be that kid, but I haven’t necessarily gotten to enjoy his childhood because I am constantly hyperaware of what might happen or what could happen or how he’s feeling.” – Female, 11 year-old son

Several parents described how feeling misunderstood by others who have not lived with diabetes and “don’t get my life” contributed to the grief of the loss of normalcy.

Desire to Control

According to parents, diabetes feels “uncontrollable”. Even though most parents reported feeling competent in caring for their child, they still experienced frustrating situations of unexplained blood sugar levels. As one mother stated, “It changes all the time. You can do everything right and [blood sugar] numbers can still be crazy.” The focus on clinical outcomes like blood sugar values and HbA1c readings leads parents to use disease control or the outcome measures of control as a measure of personal success. Parents thus work to achieve tight glucose control and they decrease their frustration with the disease by closely adhering to diabetes plans and creating safe environments.

At times, parents confided they strive to exceed clinical goals by meeting the “ideal” glucose ranges and achieving “normal” A1c levels. Overwhelmingly, parents indicated that ensuring the daily regimen was followed protects their child’s health and gives daily structure to
the uncontrollable nature of their lives. Most reported that when they are in control of diabetes and the environment in which their child lives, they are closer to ensuring their child’s survival with diabetes.

As children become more independent and begin doing more of the diabetes care tasks themselves, parents question their children more, which parents worry is interpreted as nagging. One mother shared that she automatically wants to ask her child about the day’s blood sugar readings after school, but tries to ask her about her day first. Parental nagging was mentioned as a significant source of family conflict and a negative outgrowth of control.

“I guess I am this way because I am the one responsible for her control right now. I want to do the best I can. She will be in control soon.” – Female, 16 year-old daughter

Self-Sacrifice

Parents reported personal self-sacrificing behaviors to ensure their child’s well being. These behaviors varied from sleep deprivation to never taking a vacation and these behaviors have had positive, as well as negative elements. On the positive side, parents suggested diabetes has caused them to have closer family relationships. There was a pride in the strength of the family unit and especially a pride in the courage of the child.

On the negative side, parents discussed specific family sacrifice in diabetes, mostly related to family organization and structural [time] demands. Males discussed self-sacrifice most frequently and were sensitive to the uncomfortable lifestyle changes diabetes requires. Male participants mourned the loss of private time with their partners and spoke of their desire for opportunities to be spontaneous again.
“It changed us as parents, not factoring in the kids so much, we would drop everything and go to the Bahamas. We had relatives that would take care of our older son and we could drop everything and just go. We’d go to the Bahamas, to San Francisco and we’d have no problem traveling, but with diabetes it changes it in the fact that you can’t do that.” – Male, 11 year-old son

Isolation

Feelings of isolation were reflected in several ways in this data set. Parents commented about not having support in the home with diabetes caregiving and discussed self-isolation. Of note was the way some parents imposed isolation on the young person with diabetes, specifically as they withheld information about the details and the prognosis of the disease.

“I have done a job all these years of protecting her. I have never sat down and told her all of these things. I have done a good job to make sure she doesn’t know about them. I feel that it is my job to hold on to all the scary future complications things. Every time something came up in class or a teacher talked about complications and I found out about it, I always say, “no, no they are talking about someone old.” - Female, 16 year-old daughter

“I have never discussed with her. It is hard enough to have diabetes without having to worry about that. So I take on that part and I am not telling her. Whatever she reads, fine.” - Female, 10 year-old daughter
Isolation also represents individuals who were less likely to engage in community-based activities and preferred dealing with diabetes internally rather than in an open, external way. Many participants expressed the attitude that they could handle diabetes alone and preferred little intrusion from others. These tended to be those who have lived with disease for longer periods of time. Experienced individuals tended to explain that they were capable of handling diabetes independently and don’t want to get wrapped up in the diabetes community as a way of life.

Many participants expressed isolation as a mechanism for coping. Isolation for these individuals was discussed as a protective element. Parents expressed feelings of perceived safety by not acknowledging the severity of the condition and not allowing the child to fully understand the potentially painful parts of life with diabetes. Common tones expressed include, “I don’t want diabetes to be his life” and “I don’t want her to worry.”

Exhaustion

Exhaustion was a significant discussion topic with parents as they considered the impact diabetes has had on them personally. Three distinct aspects of exhaustion were discussed: physical, emotional, and mental exhaustion.

Physical exhaustion most often related to parent sleep deprivation and disruption. Emotional exhaustion linked to the frustration related to educating others and worrying about the daily life of the child. Mental exhaustion was most often described in circumstances around the planning associated with life with disease. These exhaustion elements were often verbalized as parents talked about the disease being a “24/7” experience and that families “never get a day off.”

“I don’t think people do know that it is exhausting for the caretakers. It is time consuming and it takes a lot of thought.” – Female, 10 year-old daughter
Parents recognized the challenges of handling the daily requirements of diabetes care for both themselves and their children. Parents, as well as, their children “live it everyday”. The reality that “there is no time off from diabetes” leads to constant worry and physical fatigue.

“So, needs that are unmet, selfishly I would go back to that control and there is never a break, never ever a break.” – Male, 10 year-old son

Parents said they feared the immediate and long-term effects of diabetes. Low blood sugar episodes represent dangerous medical emergencies and parents use preventive strategies such as adhering to rigorous schedules of blood sugar checking, injections, or inflexible meal times. For example, many parents reported habitually waking or using an alarm to wake during the nighttime in order to get up and measure their child’s blood sugar in case of nighttime blood sugar lows. Many parents also used baby monitors in their child’s room to hear low blood sugar reactions into late adolescence. While these practices interrupt sleep for the parent, they also serve as emotional comforts. One parent described late night blood sugar checks as a coping mechanism. In his surmise, the exhaustion was a small price to pay for the assurance of the child’s health.

Parents talked about exhaustion around food and meal planning as well, but seemed to accept this form of exhaustion in exchange for control over circumstances. In this regard, parents described how they plan separate meals around birthday parties or family celebrations to try to keep structure, but allow for normalcy (if only in participation in events) for their child.

Interestingly, exhaustion was a top discussion topic for males. Men tended to talk about their partner’s exhaustion in great detail. Male expressions around exhaustion were vulnerable and emotional moments in the discussions. These were the only times men talked about their
worry for their partners in co-managing diabetes. Women did not discuss exhaustion in any way that related to their partners, rather their descriptions were more self-focused.

**Lack of Self-Efficacy**

Many parents expressed feelings of uncertainly and insecurity related to diabetes management. The enormity of diabetes was described as causing many parents to consistently doubt themselves. The consideration of the parental impact of diabetes allowed for many participants to recognize some of their own emotional needs.

“I think as a parent you take a lot of responsibility. We feel guilty and when you feel guilty you don’t feel empowered to get help because you feel like you are doing a bad job. Either you caused your child’s diabetes or you can’t provide some of the other things for them like housing or food, or you can’t communicate with teachers properly.” – Female, 11 year-old daughter

Parent guilt and lack of empowerment were communicated as contributors to a lack of self-efficacy. Parents even described that they were unsure if diabetes will ever get easier or better. The sadness was enormous.

“It [diabetes] is a very lonely place.” - Female, 11 year-old daughter

**Parent Coping Methods**

All parents spoke of the value of the diabetes experience in their lives and how they were proud of the strength they have gained and the example their children have set. Parents spoke about how they seek balance in their lives to cope with diabetes, how they connect with others to establish understanding and healthy relationships, and how they have a desire to give back.
Community and Support

Parents reported that the sense of community they feel when they engage with others in diabetes provides great security and emotional support. Most parents stated that they crave opportunities to connect with others who live with diabetes and speak about how they could not manage without these relationships. Community was described as the most valuable, most necessary, and most impactful aspect of life with diabetes.

“I think what helped me was talking to another mom and having a mentor. I don’t know how it happened. But, her calling me helped tremendously! I was crazy and crying that day. I was losing my mind. I was crying hysterically. I was so apologetic. I am really glad I called her back. Surrounding yourself with people who know the disease and with children who understand is important. I
honestly changed my whole circle of friends.” - Female, 10 year-old daughter

Events for families with diabetes like the Children with Diabetes conferences or Diabetes Camps serve as emotionally and physically safe places for children and their parents. Parents noted that camps and conferences were their only emotional break from the disease, as they don’t worry as much as usual because of the comfort of being surrounded by people who understand the severity of their life circumstances. These events were also described as “family gatherings,” where parents with diabetes feel connected to others in a unique and valuable way.

“We have this big, huge, gigantic diabetes family…. I can’t imagine what it would have been like if I couldn’t find another diabetic parent to talk to.” – Female, 13 year-old daughter

“Children with Diabetes is a beautiful thing. It is the only time I’ve felt 100% safe with my son since he was diagnosed.” – Female, 17 year-old son

“Camp was a life-saver that first summer.” – Male, 11 year-old son

Social connections were described as the biggest influences in care and coping with diabetes. They also became the biggest sources of information and education about living with diabetes.

“I started with the one person I knew, then I emailed about fifteen friends that I knew and started asking who do you know that has
diabetes and immediately found probably a good six or seven people who emailed me back. “ - Female, 14 year-old daughter

The challenge discussed in this category was the balance families seek. Although participation in the “diabetes community” was valuable, many participants discussed their desire to not let their lives focus only on diabetes. They struggled significantly here, even in the face of the great benefits of support. Families expressed their deep need for social connections, but also the rebellion that they have experienced from their child with diabetes. The youth tended to not have the same desire for connection as the parents.

Many parents discussed their efforts to contribute to the improvement of diabetes care. They talked about mentoring activities with other families, fundraising activities to support research, and they shared their ideas on how they would like to see professionals work to make life with diabetes better. Several families discussed how their careers have changed as a result of diabetes and how they have been inspired by the experience of diabetes.

Resilience

All of the participants agreed that diabetes has brought them the gift of relationships. All feel that life with the disease has bound them to each other in special ways. There was gratefulness in the way parents talked about the support they have received from others who also live with diabetes. In these discussions, parents spoke about strength, hope, friendships, and about devotion.

“One woman literally got off Kennedy Blvd. when she heard that I had a newly diagnosed daughter. God bless this woman, she turned around her car and was at my door in like ten minutes. And
I had never met her in my life, but she helped us to know that we could get passed the diagnosis.” - Female, 14 year-old daughter

“My friend said – it is only going to make you stronger. She said before you know it you are going to be Hercules.” “I want to ask God – Why do you think I am so strong? I guess I am she-woman!”

– Female, 10 year-old daughter

A testament to the camaraderie that emerged in the focus groups, parents discussed various websites and social media sites that have videos and commentary about the subjects of disease misunderstanding and public behaviors toward diabetes. The result was conversation about how to effectively diffuse negative situations, as the parents turned the focus groups into support group-type settings. This behavior showed the solidarity of parents as they work to support each other and fight for their children’s well being.

Parents discussed the absence of tools, education, and services that they feel are necessary for both them and their children. In these discussions, parents quickly assumed the roles of advocates and champions as they brainstormed solutions to their needs.

Qualitative Research Question Results

To return specifically to the research questions for this portion of the investigation, the overall intent was to understand the challenges, needs of, and coping strategies used by parents living with a child with diabetes. Parents most frequently indicated fear, frustration, and life stress as challenges in life with disease. To meet these challenges, parents indicated support and community amongst the most necessary elements in achieving a well-balanced, high quality life with diabetes. Parents spoke of support and community also as their main coping mechanisms in
dealing with the stress of life with diabetes. Involvement in non-profit organizations and volunteer activities were mentioned as common coping strategies. All parents in this investigation offered creative solutions they felt would help their lives with diabetes. Those solutions, discussed mainly as a brainstorming activity in focus group settings, are indicated in Table 4 below.

Table 4: Parent Ideas

<table>
<thead>
<tr>
<th>Parent Ideas / Suggestions for Tools</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vehicle stickers to indicate diabetes</td>
<td>2</td>
</tr>
<tr>
<td>RA training for diabetes in college</td>
<td>2</td>
</tr>
<tr>
<td>Life stage / transition manual – diabetes changes to expect over time</td>
<td>5</td>
</tr>
<tr>
<td>Color coded menu cards</td>
<td>1</td>
</tr>
<tr>
<td>Big brother program for people with diabetes</td>
<td>2</td>
</tr>
<tr>
<td>Resources for adults with Type 1 diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Babysitter system for families with diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Communication help for physicians and the transition from pediatric to adult care</td>
<td>3</td>
</tr>
<tr>
<td>Hotline to call for advice or help</td>
<td>2</td>
</tr>
<tr>
<td>Parent round table for how to handle diabetes in school</td>
<td>2</td>
</tr>
<tr>
<td>Way to give parental input into laws related to youth with diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Counseling on how to parent a teen with diabetes</td>
<td>3</td>
</tr>
<tr>
<td>Way to communicate with health professionals without the child present</td>
<td>3</td>
</tr>
<tr>
<td>Parent network for families with Type 1 diabetes</td>
<td>4</td>
</tr>
<tr>
<td>An app for life with diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Grandparent guide for diabetes</td>
<td>2</td>
</tr>
<tr>
<td>Fast food cheat sheets for carbohydrate counting</td>
<td>1</td>
</tr>
</tbody>
</table>
These ideas reflect the great needs felt and perceived by parents. Most strongly expressed were the concerns about the maturation process. Parents did not feel prepared and thus did not feel their children were prepared for the transition to independence with diabetes.

**Quantitative Findings**

The quantitative investigation utilized a secondary data set obtained from the Behavioral Diabetes Institute to analyze specific research questions related to parent distress. This research aimed to specifically answer the following with a population of parents of teens with diabetes:

- What are the relationships between parent distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style?
- To what degree, if at all, is parent self-efficacy associated with diabetes-related distress?
- To what degree, if at all, is emotional support associated with diabetes-related distress?
- To what degree, if at all, is parent disagreement associated with diabetes-related distress?
- To what degree, if at all, is parenting style associated with diabetes-related distress?

The variables of interest were: parent diabetes-related distress, parent self-efficacy, parent emotional support, parent disagreement, and parenting style. To seek the answers to the research questions, the secondary data set was cleaned and organized with these variables in mind, and the final grouping of variables was augmented by several relevant control variables.
**Sample Description**

The sample, a secondary data set of 332 respondents, was utilized with permission from the Behavioral Diabetes Institute in San Diego, CA. The participants all have teenage children with type 1 diabetes and thus represent a slightly different population than the qualitative data. Participants in this sample responded to a survey that included a battery of questionnaires aimed at understanding parent distress. Table 6 provides a look at the continuous and categorical data that describe the sample. Continuous data here are presented as means and standard deviations. Categorical data are presented as percent’s. Count data are presented in ranges.

*Table 5: Sample Description*

<table>
<thead>
<tr>
<th>Variable (n)</th>
<th>Mean / Median or Percent and Standard Deviation or Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent distress (n = 332)</td>
<td>1.4 ± 0.9 (1-4 range)</td>
</tr>
<tr>
<td>Gender (n = 332) Male</td>
<td>11.4% (n=38)</td>
</tr>
<tr>
<td>Gender (n = 332) Female</td>
<td>88.6% (n=294)</td>
</tr>
<tr>
<td>Age (n = 332)</td>
<td>47.2 ± 5.9</td>
</tr>
<tr>
<td>Time since diagnosis (n = 332)</td>
<td>6 (0-19 years)</td>
</tr>
</tbody>
</table>

The majority of participants were female (88.6%). The median age was 47 and the median length of experience with diabetes was 6 years with a range of 0-19 years (0 indicating new or early onset of diabetes).

To better understand the parent sample, it is beneficial to examine some details about the children they are parenting. Table 6 describes the teens with diabetes as reported by the parents.
The average age of the youth with diabetes is 15 years. A relatively small percentage of the youth experience disabilities, psychological disorders, anxiety issues and depression along with school days missed.
with their diabetes. Of these, depression, at 12.4%, was the most frequently reported issue from this parent report.

**Variables**

The internal validity of the battery of questionnaires had been previously established through the use of Cronbach’s alpha and cited in a conference presentation on the data set (Hessler et al, 2012). Early analysis of the distress data by the Behavioral Diabetes Institute validated the 20-question scale (Table 2) used to determine distress scores for the participants. In this examination of the self-report data from parents, the mean score for the outcome variable of distress was 1.4 (0-4). On the Likert scale for this questionnaire, 0 means “Not at all” and 4 means “A great deal.” The mean scores of the distress question responses were then examined further to better understand the score distribution (Table 7 and Figure ). The distress scores are skewed toward less distress.

*Table 7: Distress Score Distribution*

<table>
<thead>
<tr>
<th>Distress Score</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (0&lt;1)</td>
<td>137</td>
<td>41.3</td>
<td>41.3</td>
</tr>
<tr>
<td>2 (1.1&lt;2)</td>
<td>115</td>
<td>34.6</td>
<td>75.9</td>
</tr>
<tr>
<td>3 (2.1&lt;3)</td>
<td>65</td>
<td>19.6</td>
<td>95.5</td>
</tr>
<tr>
<td>4 (3.1&lt;4)</td>
<td>15</td>
<td>4.5</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The graphic below shows another view of the distress mean distribution. The distress scores for the data set are skewed toward less distress. Analysis for the skewness and kurtosis were run on the sample. The results found skewness = 0.583 and kurtosis = 2.542.
Four independent variables were chosen for this investigation. Each variable corresponds with a specific questionnaire in the battery of questionnaires provided to parents. The parenting style variable has three sub-variables to represent the components of parenting style considered.

The mean scores and the standard deviations of the independent variables of interest are reported in Table 8. Self-efficacy and authoritative parenting have the highest mean scores, but should not be compared to each other. Here the mean scores should only be considered individually as each of the variables is represented by different measurement scales within the large battery of questionnaires provided to parents.

The self-efficacy score corresponds to questions about the confidence parents have in their and their child’s diabetes knowledge. The score of 2-3 on the Likert scale indicates a parent
response of “A Little Confident” (2) to “Somewhat Confident” (3). On this scale, (4) indicated “Very Confident” as a response.

The parent disagreement score corresponds to questions about co-parenting and co-management of diabetes. On this scale, 0 indicated “Never” and 4 indicates “Very Often.” The questions gauge conflict associated with diabetes.

Parent emotional support refers to the questionnaire that asks about feelings of support and how much support the parent has personally received. On this scale responses are indicated between 0-4 with 0 meaning “None” and 4 indicating “A Great Deal.”

The parenting style scores were gathered from collections of parent responses to a modified version of the Parental Authority Questionnaire (Reitman, Rhode, Hupp & Altobello, 2002). In this questionnaire, parents scored their parenting beliefs on a Likert scale of 1-5 for each parenting style question. A score of 1 indicated the respondent “Strongly Agrees” with the assertion in the question, while a score of 5 indicated the respondent “Strongly Disagrees”. In the mean score tabulations, a low score indicated a positive relationship with the dependent variable. In the parenting style category, the low score indicated that the dependent variable had a positive agreement with the parenting style being questioned. (For example: A score of 1 on the parenting style questionnaire means most authoritarian, while a score of 5 means least authoritarian.) The higher mean score (3.1) of authoritative parenting indicates a “somewhat” selection from parents. This is neither agree or disagree according to the Likert scale used. (Authoritative parenting is warm and collaborative parenting by definition.)
Table 8: Independent Variable Descriptive Statistics

<table>
<thead>
<tr>
<th>Variable (n)</th>
<th>Mean / Standard Deviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Self-Efficacy (n = 329)</td>
<td>2.3 ± 0.6</td>
<td>Higher score = More Confident</td>
</tr>
<tr>
<td>Parenting Style Authoritarian (n = 328)</td>
<td>1.5 ± 0.6</td>
<td>Lower score = More Authoritarian</td>
</tr>
<tr>
<td>Parenting Style Authoritative (n = 327)</td>
<td>3.1 ± 0.5</td>
<td>Higher score = Less Authoritative</td>
</tr>
<tr>
<td>Parenting Style Permissive (n = 327)</td>
<td>1.6 ± 0.6</td>
<td>Lower score = More Permissive</td>
</tr>
<tr>
<td>Parent Emotional Support (n = 327)</td>
<td>1.8 ± 0.8</td>
<td>Lower score = Less Support</td>
</tr>
<tr>
<td>Parent Disagreement (n = 259)</td>
<td>1.2 ± 0.8</td>
<td>Lower score = Less Disagreement</td>
</tr>
</tbody>
</table>

**Bivariate Statistics**

To better understand the sample and answer the overarching research questions about associations, bivariate statistics are shown in Table 9. Nearly all of the variables correlated with the dependent variable of distress with a p value of <.05 (significance noted with an *). The strongest positive correlation was between distress and parent disagreement. The strongest negative correlation was between distress and parent emotional support.

The correlations evidenced in Table 9 partially answer the research questions posed. It is difficult to assign cause and effect assumptions to this data set, as the data were collected with exploratory intent. A possible explanation of the negative correlation of parent emotional support with distress is that the less emotional support a parent has, the more distress the parent experiences. It should be noted that this is not the exclusive explanation though.
## Table 9: Variable Correlation Matrix

<table>
<thead>
<tr>
<th></th>
<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>Distress</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent gender</td>
<td>0.15*</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Age</td>
<td>-0.13*</td>
<td>-0.23*</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Self-Efficacy</td>
<td>-0.29*</td>
<td>-0.09</td>
<td>0.05</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting Style Authoritarian</td>
<td>-0.24*</td>
<td>-0.02</td>
<td>-0.21</td>
<td>-0.11</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting Style Authoritative</td>
<td>0.0</td>
<td>0.008</td>
<td>0.05</td>
<td>0.15*</td>
<td>-0.09</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting Style Permissive</td>
<td>-0.10</td>
<td>0.08</td>
<td>0.03</td>
<td>0.08</td>
<td>-0.21*</td>
<td>0.1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting Emotional Support</td>
<td>-0.65*</td>
<td>-0.09</td>
<td>-0.02</td>
<td>0.32*</td>
<td>-0.01</td>
<td>0.09</td>
<td>0.1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Disagreement</td>
<td>0.48*</td>
<td>-0.03</td>
<td>-0.002</td>
<td>-0.21*</td>
<td>0.27*</td>
<td>-0.08</td>
<td>-0.06</td>
<td>-0.37*</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td>0.14*</td>
<td>-0.12*</td>
<td>0.15*</td>
<td>0.05</td>
<td>-0.1</td>
<td>0.007</td>
<td>0.08</td>
<td>-0.29*</td>
<td>0.16*</td>
<td>1</td>
</tr>
</tbody>
</table>
Likewise, the correlation of authoritarian parenting style with distress indicates that the more authoritarian a parent is, the more distressed they may be (this parenting style was reverse coded in the data set). Because this investigation is exploratory and did not seek to identify the causes of distress, it is unclear what the root cause of the distress is from these data.

Of the control variables, parent age is most significantly correlated with distress. The younger a parent is, the more likely they were to be distressed. Distress also was shown to increase with the passage of time or duration of disease.

Therefore, the correlations show that elevated levels of parent distress are linked to less support, more disagreement with the other parent, more authoritarian parenting style beliefs, duration of diabetes, parent age and parent gender.

**Multivariable Statistics**

Multivariable statistics were used to answer the research questions. Linear Regression was chosen to examine the relationship between the dependent and independent variables. The full linear regression model is exhibited in Table 10. In this version of the regression model, all variables are shown.

After examination of the full model, a modified model was run and a stepwise elimination process employed. (Table 11) Through the backward stepwise elimination process, the variables of interest were fitted for the final regression model. This process allowed for a broad examination without having to go through a process of prediction, which could lead to errors and assumptions. Backward stepwise elimination at 0.1 and 0.05 level of significance produced equal results. Through this process, it was found that permissive parenting style and self-efficacy were not significant. Of the control variables, time since diagnosis was also deemed not significant and thus not included in the final model.
Table 10: Full Regression Model

|                | Coef.       | Std. Err. | t      | P>|t|  | [95% Conf. Interval] |
|----------------|-------------|-----------|--------|------|---------------------|
| Parent Gender | .2253315    | .1017216  | 2.22   | 0.028| .0249871 .425676    |
| Parent Age    | -.0127693   | .0065304  | -1.96  | 0.052| -.0256312 .000926   |
| Parent Self-Efficacy | -.0389514 | .0676448  | -0.58  | 0.565| -.1721803 .0942775  |
| Parent Authoritarian | .2408768 | .0715661  | 3.37   | 0.001| .0999247 .381829    |
| Parent Authoritative | .1388401  | .0705384  | 1.97   | 0.050| -.000088 .2777681   |
| Parent Permissive | -.0269034 | .0695915  | -0.39  | 0.699| -.1639664 .1101595  |
| Emotional Support | -.5356967 | .0559039  | -9.58  | <0.001| -.6458016 -.4255919 |
| Parent Disagreement | .2481428 | .0512351  | 4.84   | <0.001| .1472334 .3490522   |
| Time Since Diagnosis | .0018711 | .0089916  | 0.21   | 0.835| -.0158382 .0195805  |
| _cons          | .9820244    | .1932924  | 5.08   | <0.001| .6013279 1.362721   |

---

Table 11: Modified Linear Regression Model

|                | Coef.       | Std. Err. | t      | P>|t|  | [95% Conf. Interval] |
|----------------|-------------|-----------|--------|------|---------------------|
| Parent Gender | .2220747    | .0989878  | 2.24   | 0.026| .027126 .4170235    |
| Parent Age    | -.012888    | .0064735  | -1.99  | 0.048| -.025637 .0001389   |
| Emotional Support | -.5481596 | .0534234  | -10.26 | <0.001| -.6533728 -.4429463 |
| Parent Authoritarian | .2466809 | .0711349  | 3.47   | 0.001| .1065862 .3867755   |
| Parent Authoritative | .1322587 | .0702845  | 1.88   | 0.061| -.0061611 .2706786  |
| Parent Disagreement | .2508313 | .0501221  | 5.00   | <0.001| .1521198 .3495429   |
| _cons          | .9873555    | .1871464  | 5.28   | <0.001| .6187852 1.355926   |

---

In this modified regression model, we see parent emotional support, authoritarian parenting style, and parent disagreement as the strongest elements. The low p values of these variables point to the strength of the model and the associations with distress.
In this model, the inclusion of parent disagreement as a variable challenged the overall N. Parent disagreement has 22% missing data from the overall data set. Because of this, a sensitivity analysis was performed through a backward stepwise elimination of the variables. The results from this process were unchanged and the variables maintained significance. This led to the decision to keep parent disagreement in the model and to also run the model with the reduced data set (n = 259).

To verify the creation of the linear regression model and the fit of the variables, two additional tests were conducted. The Ramsey test examined the omitted variables and the results of this test required no changes to the regression model (p = 0.15). The specification error test determined that the proper number of variables were utilized in the final regression model. The Ramsey and specification error tests demonstrated that the selected variables were sufficient for the regression model.

Table 12: Specification Error Test; Number of Observations - 259

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>Df</th>
<th>MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>96.4222576</td>
<td>2</td>
<td>48.2111288</td>
</tr>
<tr>
<td>Residual</td>
<td>89.894422</td>
<td>256</td>
<td>.351150086</td>
</tr>
<tr>
<td>Total</td>
<td>186.31668</td>
<td>258</td>
<td>.722157673</td>
</tr>
</tbody>
</table>

F( 2, 256) = 137.29
Prob > F = 0.0000
R-squared = 0.5175
Adj R-squared = 0.5137
Root MSE = .59258
Table 13: SPSS Output – Specification Error Test

| Distress | Coef.  | Std. Err. | t  | P>|t| | [95% Conf. Interval] |
|---------|--------|-----------|----|---|------------------------|
| _hat | .9057474 | .2245317 | 4.03 | <0.001 | .463583 | 1.347912 |
| _hatsq | .0321213 | .0737029 | 0.44 | 0.663 | -.1130199 | .1772626 |
| _cons | .0569537 | .1593312 | 0.36 | 0.721 | -.2568131 | .3707205 |

The variables in the model were also tested for multicolinearity. All variables were found to be independent and not colinear. This adds to the strength of the model.

Table 14: Multicolinearity

<table>
<thead>
<tr>
<th>Variable</th>
<th>VIF</th>
<th>R-sq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Gender</td>
<td>1.11</td>
<td>0.09</td>
</tr>
<tr>
<td>Parent Age</td>
<td>1.15</td>
<td>0.13</td>
</tr>
<tr>
<td>Parent Self-Efficacy</td>
<td>1.14</td>
<td>0.12</td>
</tr>
<tr>
<td>Parenting Style Authoritarian</td>
<td>1.2</td>
<td>0.17</td>
</tr>
<tr>
<td>Parenting Style Authoritative</td>
<td>1.04</td>
<td>0.03</td>
</tr>
<tr>
<td>Parenting Style Permissive</td>
<td>1.08</td>
<td>0.07</td>
</tr>
<tr>
<td>Parent Emotional Support</td>
<td>1.39</td>
<td>0.27</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

Discussion

This chapter discusses the results of a mixed methods investigation into parent distress in life with a child with type 1 diabetes. In this chapter, the results of the investigation and contributions of this research to theory, public health practice, and clinical practice will be described. Future research directions will also be highlighted.

Research Objectives

The purpose of this study was to highlight parent distress in diabetes, identify factors associated with distress and to show how public health and clinical professionals can assist parents in coping with their child’s diabetes and living positively as a family unit. The quantitative research conducted showed significance in connecting parent distress to parent emotional support and parent disagreement in parents with teenage children with diabetes. The qualitative investigation showed parent distress in three categories: systems, relationships and emotions related to life with a child/teen/young adult with diabetes.

Triangulation

The study results point to many factors that can be considered contributors to parent distress. Tying together data from both sections of this research one can identify fractured parent/child relationships (authoritarian parenting), family conflict (parent disagreement), isolation or lack of support (emotional support), and overall fear to distress (Haugsvedt, 2011; Williams, 2009; Woolfson, 2005). These findings are not surprising. This study
reinforces previous work by Williams (2009) and Jaser (2011), on the significance of family conflict in diabetes management and outcomes. This study also echoes evidence from Harbaum (2008) and Woolfson (2005) related to the importance of parenting style in the consideration of care for families with chronic illness. Parents who exhibit parenting styles that are warm and collaborative (authoritative) are least likely to be distressed, whereas those who are authoritarian in approach to parenting are more likely to be distressed. This makes sense, as those who have expectations without flexibility or are experiencing high stress are most likely to be disappointed with less-than-perfect outcomes. Diabetes, as parents report in this study, is an inexact science and requires a flexible, patient approach. It [diabetes] often has a “mind of its own” and thus parents have to learn to be flexible to emotionally survive. This proves true in family relationships as well. Warm, collaborative family relationships are the strongest.

The examination of distress occurred here in two separate ways. The samples were different in composition and thus the parents represented in the two samples may have experienced different concerns and realities with diabetes. That limitation being acknowledged, it is safe to say that parents both expressed great need and showed tremendous resilience. The need expressed was emotional, physical, and information-related. The resilience ties together the findings related to emotional support with the first person information about coping from parents. The discussion will therefore now look at connections in the data from emotional stress to the necessity of support.

*Emotional Stress*

There is significant emotional stress associated with diabetes. Parents grapple with unrelenting fear, frustration, and significant sadness. In all of the qualitative discussions, parents talked about their fears related to diabetes. The specifics of fear varied, but it was clear that parents universally struggle. The sad reality is there is little for parents in the form
of programs or remedies to ease the heartache caused by this fear. In diabetes, fears compound, grow, change, and they never fully go away. This research reinforces findings by Barnard (2010) that parents need assistance with fear-based behaviors and perceptions. This study also underscores the findings from Cunningham (2010) that caregiver perception is a powerful element of caregiver distress.

Further evidence of emotional stress comes from the inability of parents to identify their own needs. Without fail, each parent in the qualitative portion of the study struggled to talk about their needs outside of their child’s needs. The emphasis and concern for the youth with disease was overwhelming for parents and their concern was so deep that nothing else mattered except care for their child. This may also correlate to findings from Cunningham (2010) regarding the perceived intensity of the burden of diabetes for caregivers. Eventually in each interview, parents would get to an emotional point where they would recognize that there are unmet needs in the family outside of the child with disease. This inability to see personal (parent) need may be an outgrowth of the intensity of the disease experience and the energy encompassed in maintaining the child’s health (Anderson, Brackett, Ho, and Laffel, 1999; Sonneveld, Strating, van Staa, & Nieboer, 2013).

**Control**

Control is evidenced in many ways in this study. In the qualitative portion of the study, control is discussed as both clinical management of diabetes and control of environment; at times, control is suggested related to information delivery, as well. In the quantitative portion of the study, control is manifested in some of parenting style results, as authoritarian parents tend to be very controlling. The association between the two sections of the study cannot be overstated though. The populations are different and thus there may be contextual elements that are not fully understood by these data sets.
Regardless, parents walk a difficult line in helping their child live with and mature with diabetes. So much control is expected of parents as they must keep their child alive, yet at the same time parents are expected by society to behave in non-controlling and engaging ways with allowing their child to grow and mature (Monaghan, 2012). The literature points to evidence regarding collaborative parenting and collaborative diabetes management with positive diabetes health outcomes, yet the challenge persists in families as they decide how to transition control and responsibility in life with diabetes (Jaser, 2011; Wiebe et al, 2005). Continued parent involvement is shown to be associated with better diabetes care (Jaser, 2011), and thus professionals need to understand family functioning to best assist parents in proactive engagement with youth.

The best example of the conflict of control for parents comes from a discussion related to the maturation of youth where parents explained that they want their child to thrive even though they have diabetes, yet at the same time they also want their child to be understood as a “victim” of the disease. These competing desires appear to be a source of conflict in the family and confusion for both the parents and the child.

In the qualitative interviews, many parents seemed to associate the sense of “control” with the “well-being” feeling that the environments they (i.e., parents) control are the safest and best for the youth with diabetes. This can have a negative outgrowth for the youth, yet is often used as a coping mechanism for the parents. Parent controlling behaviors, although well meaning, can be interpreted by youth as negative and over-protective. Parents, though, feel better when they work to create the best life scenarios possible for their children. This, however, may inhibit growth for the youth as independence can be inhibited.

Within the category of control, it is appropriate to consider family conflict and parental disagreement under the broader terminology of family functioning. The literature has shown that family functioning is strongly associated with diabetes physical and
psychological functioning (Jaser, 2011). Research indicates that warm family environments are associated with the best diabetes outcomes, assisting youth in achieving better diabetes control (Berg, 2008; Whittemore, 2012). Fractured families lead to distress, which can lead to less optimal diabetes management.

**Parenting Style**

It is not surprising that authoritative parenting is correlated with distress. Parenting style results in this study are similar to findings from Woolfson (2005) in that there is more family conflict and more distress when parents employ an authoritarian parenting style. “Nagging” behaviors and overly protective behaviors may be encompassed in this category, but specific results of how and why parents use authoritarian parenting was unclear. It could be that parents are authoritarian because of a difficult teen or because of mismanagement of diabetes or because of the parent’s individual nature. More investigation is necessary to adequately understand this dynamic. It is clear, however, that parents and health professionals would benefit from heightened awareness of parenting style behaviors.

Communication coaching may prove helpful for families struggling with diabetes.

**Support**

Throughout both sections of this research, there was a strong emphasis from parents on the significance of support in their lives with diabetes. Similar to a study by Woolfson (2005), this investigation also found that a lack of emotional support was correlated with distress, suggesting that more access to support is necessary for families. A significant challenge seemed to be in identifying where parents can access support. Parents crave support from a variety of sources, and frequently look to health professionals for advice on how to connect with others. This signals a significant opportunity in the diabetes clinical community.
Interestingly, parents discussed involvement with non-profit organizations at length in this study. They spoke of the benefits and the disadvantages, and how in this arena, too, there is great opportunity. Parents began their journey in life with diabetes as fundraisers for diabetes science, but then they started to seek programmatic solutions. When they realized the solutions they needed were not available, parents tended to disengage with organizations. Youth maturity and involvement in collegiate activities were mentioned as shifting points for parent involvement and engagement with organizations. This signals another opportunity, as parents seek relevance to every day life with disease.

The growing pains of maturation are a significant issue for parents. Parents openly discuss the confusion that comes with the maturation process in life with diabetes. The systems in our culture do not seem to be attuned to the specific needs of this population – both youth and parents.

**Resilience**

The expressions of resilience in this study were fascinating to hear and observe. Parents repeatedly expressed how they have “handled” diabetes or that they are no longer as affected by the condition. They spoke frequently about how diabetes has made them better and their children stronger. Although this expression is encouraging, over time it seemed like a learned behavior. Although the words expressed were overwhelmingly positive, at the same time parents seemed to be convincing themselves that diabetes isn’t that bad. They talked about the gift of relationships, but then also shared stories of desperation. This resilience phenomenon has been shown in other health conditions (Horton & Wallander, 2001; Zauszniewski, J., Behet, A., & Suresky, J., 2008; Yi, J., 2008). In light of a reality where a cure is not imminent, this may be an attitude that preserves parent psyche and helps them cope. Resilience has also been shown to impact health outcomes (Yi, 2008). This seemingly learned behavior may have clouded some of the findings in this study, as it was
unclear how authentic the resilience was and how long parents had felt or exhibited such confidence. It is not well known when parents learn to be resilient in life with diabetes.

There are many other contributors to distress identified in the qualitative findings, but they are not generalizable, as each family experiences diabetes differently. For example, sibling issues were isolated to families with multiple children or transition/college issues were central to families with older children. Even exhaustion, a universal conversation topic, was communicated in different ways by parents at different stages in the life course. Still, it is clear from this investigation that there are many areas in which parents need service to help manage life with diabetes.

**How to Help**

Parents shared in the qualitative portion of the investigation that they are fearful of life with diabetes, they feel unprepared for the future, they desire stronger relationships with the health team, and that they need practical guidance on living well with diabetes. This input from parents holds great value. They provide for us, as seen in Table 4, ideas on how parents’ needs could be met.

**Contributions to Theory**

To better contextualize the information learned, theory can be applied as a guide. The information from the qualitative research connects to theoretical constructs and philosophies found in the Social Ecological Framework and the Social Cognitive Theory (SCT). Theory was not used a priori to ground the research, but rather, theoretical themes emerged from the data that are important for future work.

Specifically, the Social Ecological Theoretical framework is dominant here as the research explores how individuals and their families live with the disease. All categories of
influence (Intrapersonal, Interpersonal, Community, Organizational, and Policy) are evidenced in the qualitative data.

SCT is made up of three main categories: person, behavior, and environment, and there are several constructs within each category. All SCT categories are also evidenced in the qualitative data. The table below (Table 15) visually links qualitative themes with theories and theoretical constructs.

*Table 15: Evidence of Theory in Data*

<table>
<thead>
<tr>
<th>Qualitative Theme</th>
<th>Social Ecological Level</th>
<th>SCT Category</th>
<th>SCT Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>Inter</td>
<td>Environment</td>
<td>Observational Learning</td>
</tr>
<tr>
<td>Education / Knowledge</td>
<td>Intra, Inter, Community,</td>
<td>Environment</td>
<td>Self-Efficacy, Observational</td>
</tr>
<tr>
<td>Emotional Strain</td>
<td>Intra, Inter</td>
<td>Person</td>
<td>Self-Efficacy, Self-Regulation</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>Intra, Inter</td>
<td>Behavior</td>
<td>Incentive Motivation</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>Intra, Inter</td>
<td>Behavior, Environment</td>
<td>Facilitation, Collective Efficacy</td>
</tr>
<tr>
<td>Fear</td>
<td>Intra</td>
<td>Person</td>
<td>Self-Efficacy</td>
</tr>
<tr>
<td>Frustration</td>
<td>Intra, Inter, Community, Policy</td>
<td>Person</td>
<td>Self-Efficacy, Self-Regulation</td>
</tr>
<tr>
<td>Guilt</td>
<td>Intra</td>
<td>Person</td>
<td>Self-Efficacy, Self-Regulation</td>
</tr>
<tr>
<td>Isolation</td>
<td>Intra</td>
<td>Behavior</td>
<td>Self Regulation</td>
</tr>
<tr>
<td>Resilience</td>
<td>Intra, Inter</td>
<td>Behavior, Person</td>
<td>Self-Efficacy</td>
</tr>
<tr>
<td>Safety</td>
<td>Inter, Community, Policy</td>
<td>Environment</td>
<td>Outcome Expectations</td>
</tr>
<tr>
<td>School Issues</td>
<td>Inter, Community, Organizational,</td>
<td>Environment</td>
<td>Outcome Expectations, Self-</td>
</tr>
<tr>
<td>Support</td>
<td>Intra, Inter</td>
<td>Person, Behavior, Environment</td>
<td>Collective Efficacy, Observational</td>
</tr>
</tbody>
</table>

The most frequent construct from SCT identified in the qualitative data was self-efficacy. The meaning of self-efficacy shifts broadly throughout the data. At times the term matches the traditional definition of an individual’s confidence in carrying out specific skills
or tasks, and at other times, it represents the lack of confidence and the need for greater self-efficacy, in general in diabetes care. Self-efficacy is almost always used to indicate intrapersonal emotions, or how one feels about his or her own ability.

The second most frequently identified construct from SCT was self-regulation. This indicates the capacity to recover from the shock of diagnosis and the potential participants showed in being about to handle stress. Although linked to guilt, frustration, and emotional strain, self-regulation was explained in two ways. First, there was the challenge to self-regulate, and then there was the celebration of the effectiveness of self-regulation. At the beginning of life with diabetes, parents must self-regulate emotion, language, and behavior as a means to influence child adaptation to life with disease. Post diagnosis, regulation becomes more dominant in every day diabetes maintenance behaviors. This is reflected in how parents discuss being constantly prepared for and exhausted by life with diabetes, as well as how they navigate the stress of their child’s participation in school systems. As noted in Table 16, many times self-regulation and self-efficacy appear together. This may represent meaning on multiple social ecological levels. As noted before, self-efficacy most often relates to feelings about one’s self, while self-regulation can have meaning in both the intrapersonal and interpersonal social ecological levels.

Collective efficacy represents the belief (or lack thereof) that the participants exhibited collective efficacy as part of the family unit, the diabetes community, and/or their relationship with the health care team. Most often this is used to express the necessity of support. At times this was described in a negative context as participants expressed a need for basic, more or greater support. For those who had experience within the diabetes community, collective efficacy identified the value they placed on social activities with others who also live with diabetes.
The frequency and variety of the SCT categories and constructs indicated in Table 16 above shows the dynamic interplay present. Further, the use of the Social Cognitive Theory can be helpful in identifying areas for future investigation or program development. For instance, explicit use of SCT would aid researchers in identifying challenges families face with behaviors (parents and youth), as well as the context of their environments. Greater understanding about environment and how family dynamics might be influenced because of environment would be useful. Some of this is represented in this sample through expressions about collective efficacy, but the parent emphasis on social support leads one to believe there is much more to explore.

In the quantitative data, theory is also evidenced. The significance of parenting style, emotional support, and family dynamics also connects with SCT. The SCT themes of behavior, person, and environment are represented in the statistical data. This signals further opportunity for research grounded in theory to create solutions that serve parents and families.

Conclusions

From the results of this study, the following conclusions are offered:

- Parenting style can suggest parent distress in diabetes.
- Understanding parental disagreement or family conflict may point to opportunities to assist families with coping.
- Understanding parent emotion may provide clues to diabetes distress in families.
- Measuring support can aid in understanding the emotional well being of families.
• Both health professionals and families living with diabetes should clearly understand available coping mechanisms, as well as coping mechanism being utilized by the family.

• Advice on coping mechanisms and support should be a part of the health care plan for the family with diabetes.

• Health professionals should be able to recognize the positive and negative outcomes related to coping choices.

• Systems improvement (school system, health system, diabetes organizations) may aid in the diabetes management and psychological functioning of families.

Public Health Significance

The mission of public health is to assure conditions to provide opportunities for population health (IOM, 1988). It is well recognized that health is not only evidenced in the physical form, but is also reliant on quality of life, emotional, and mental health (Hanlon & Pickett, 1984). This research is significant to public health practice because little research has been done exploring the relationship of caregivers to disease outcomes and quality of life in diabetes. With the prevalence of diabetes and the increasing incidence of Type 1 diabetes, public health professionals must be prepared to service this aspect of the population.

With approximately 26 million people with diabetes, including nearly 3 million with Type 1 diabetes, there are an equal if not double number of caregivers working to support the individuals with disease (CDC Diabetes Fact Sheet, 2011). There is opportunity for public health professionals to engage in the treatment of the more then 52 million caregivers impacted by diabetes by creating surveillance systems and assessment tools for clinicians that identify families in need or families experiencing unusually high levels of distress. Interventions crafted with a theoretical backbone and a population context would enhance the
diabetes field and contribute to the understanding of broader challenges in diabetes. Program
development and evaluation are other areas ripe for public health infusion. It is clear from
this investigation and the literature that a need exists within family systems when chronic
disease is present (Kim & Schulz, 2008). It can be argued that this is a snapshot of a larger
population misunderstanding (caregivers) that needs further investigation.

Clinical Significance

From a clinical perspective, results from this study could have a significant impact on
clinical practice behaviors. Much was gained from the perspectives of parents of youth with
diabetes in both research sections. This information, especially when paired with the creative
commentary from parents on their clinical education desires, can aid in the creation of new
initiatives and processes in clinical settings. The information also provides opportunity to
further research ways to serve family units by identifying distress and offering support
designed for specific types of parents.

Specific clinical practice recommendations include:

- One-on-one time between parents and the provider(s) during clinical visits
  would allow for greater understanding of social realities and family dynamics.
- Specific family training on diabetes techniques, basics, and communication
  would aid in preserving or even repairing potentially damaged family
  relationships and misunderstandings.
- Greater access to clinical results for parents – especially during the transition
  years.
- Re-envisioned processes in diabetes education and information delivery that
  allow for enhanced family engagement in diabetes education, real life diabetes
training, and anticipatory care (transitions) would demystify and enhance diabetes family life.

- Specific emphasis from the clinical team on coping mechanisms (especially peer networks) and positive behaviors for each member of the family would aid in family recovery from the shock of diagnosis and allow families to gain knowledge of resources that could help them manage daily life with diabetes.

**Limitations**

Even though the results had several significant findings, the limitations associated with this study require careful interpretation. The major limitations, discussed in Chapter 1, include selection bias and researcher bias. Selection bias may have lead the results to be overly positive and significant because the participants represent an engaged portion of the diabetes community. The composition of the sample may be less representative because of participant self-selection. Another sample limitation to consider is the sample size. Although the researcher felt saturation was met with the qualitative sample, both research section samples may have benefited from larger, more diverse participation. An additional limitation is missing data. In the quantitative data set, the N was reduced due to missing values. Instead of the full 332 respondents in the sample, this investigation can only rely on a full sample of 259 completed questionnaires. There was also the limitation of the differences in the samples. The quantitative sample focused on parents of teens with diabetes, whereas the qualitative sample was broader in population inclusion (children ages 10-25).

In the quantitative results, another limitation can be found in the use of mean scores to understand the data. Mean scores are limited in their interpretative use and may not have completely represented the population or the context of behaviors questioned. For instance, authoritative parenting could relate to parent-chosen behavior or could be a combination of
other familial and child factors. This investigation did not seek deep information relative to the motivation for parenting style or the contextual factors associated with the family environment that may contribute to the chosen parenting style.

It must also be noted that a “member” of the diabetes community, thus potentially skewing the information provided in the qualitative portion, conducted this investigation. There is potential that the attitudes and expressions shared by parents were more emotional because of the bond parents felt with “someone who understands them.” The researcher chose to emphasize parent distress and coping in the qualitative portion of the research because of the high individual value the researcher places on first person experiences. This methodology may have also influenced the research results. The researcher also urged the creation of and design of the collection of questionnaires for use in the quantitative portion. Much of the research gathered was initiated because of the researchers emotional experiences with diabetes. Although every effort was taken to avoid bias, it cannot be completely ruled out, as the topic was deeply personal for the researcher.

**Recommendations for Future Research**

The qualitative work in this research provided rich information for developing ideas, measures, and hypotheses that can be tested in future research. The data for this project were cross-sectional, but it would be beneficial to follow up this study with longitudinal research. For example, it would benefit the field to collect distress data at multiple time points in a longitudinal study to determine if and how distress changes with disease duration.

Future studies should consider a broader range of outcomes to assess well being and resilience of those with Type 1 diabetes and the family members of those with Type 1 diabetes. It would also be worthwhile to identify and measure a broader range of factors associated with diabetes distress with a larger sample. Use of or the creation of standardized
measures for such an investigation would be a welcome addition to the field. In diabetes psychology, there is presently a lack of standardization.

Sample recommendations include a broader sampling for males and more ethnic diversity in the sample. Collection and analysis of socioeconomic data may also be beneficial. Specific understanding about past family participation in diabetes education or the access to diabetes care services would also be elements to consider in future research.

Further use of theory should also be considered in future research. Albert Bandura stated in 1977 that, “behavior is learned from the environment through the process of observational learning.” Thus, social learning and social cognitive perspectives would be useful additions to diabetes education.

It is clear that parent distress is significant in the life with a child with diabetes. The diabetes community would be well served to develop interventions to assist families in coping with life with a chronic disease. If the families are not doing well with the disease, how can the children ever do as well as we hope? Future research into the topics of parent distress and family functioning will accelerate the diabetes field to new understandings of how to best help individuals with disease in the environment in which they live and function. Without this type of consideration, diabetes care will be incomplete. For the members of the diabetes community, the patients, this type of research would be a welcome addition to the excellent physical care already available.
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APPENDICES

Appendix A: Literature Review PRISMA Decision Tree
Appendix B: Literature Review Search Methods

Search Methods

In this systematic review, 47 articles were examined. All articles focused on either distress or stress in caregivers and families managing diabetes. Here, the aim is to show prior research on parental distress and parental expectations related to diabetes. In this review, particular attention is paid to distress predictors with the intention of identifying intervention strategies and recommendations for future research.

The literature search encompassed results from four databases: PubMed, CINHAL, PsychINFO, and Web of Science. Within PubMed, there were three searches conducted to augment the research results aiming for complete assessment of the literature on the topic. In the three PubMed searches, the terms “coping”, “distress” and “stress” were interchanged based on guidance from the MeSH database of search terms. Keywords varied in each of the four databases due to the specific database’s common terms. The key words and database search results are detailed in the chart below, as well as in the PRISMA (Moher et al, 2009) chart in Appendix A.

Table 16: Literature Search Chart

<table>
<thead>
<tr>
<th>DATABASE</th>
<th>Keyword 1</th>
<th>Keyword 2</th>
<th>Keyword 3</th>
<th>Keyword 4</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PubMed</td>
<td>Type 1 Diabetes = 4734</td>
<td>Parent Child Relation = 73</td>
<td>Coping = 12</td>
<td>= 12</td>
<td></td>
</tr>
<tr>
<td>PubMed 2</td>
<td>Type 1 Diabetes = 4734</td>
<td>Parent Child Relation = 73</td>
<td>Stress = 23</td>
<td>= 23</td>
<td></td>
</tr>
</tbody>
</table>
Table 16: Literature Search Chart (continued)

<table>
<thead>
<tr>
<th>DATABASE</th>
<th>Keyword 1</th>
<th>Keyword 2</th>
<th>Keyword 3</th>
<th>Keyword 4</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PubMed 3</td>
<td>Type 1 Diabetes</td>
<td>Parents</td>
<td>Distress</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>= 4734</td>
<td>= 198</td>
<td>= 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PsychINFO</td>
<td>Type 1 Diabetes</td>
<td>Parent and</td>
<td>Coping</td>
<td>Distress = 5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>= 1069</td>
<td>Child</td>
<td>= 19</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>= 203</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CINAHL</td>
<td>Type 1 Diabetes</td>
<td>Psychosocial</td>
<td>Parents</td>
<td>Distress = 6</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>= 7599</td>
<td>Factors</td>
<td>= 135</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>= 712</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Web of Science</td>
<td>Type 1 Diabetes</td>
<td>Parent Child</td>
<td>Distress</td>
<td>Exclude: Occupational/</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>= 50,990</td>
<td>= 620</td>
<td>= 23</td>
<td>Environmental Journals</td>
<td></td>
</tr>
</tbody>
</table>

Articles were chosen based on criteria set forth by the researcher. After collection of the initial search results, all articles were examined for relevance according to the stated purpose of the systematic review. Upon abstract examination, 12 articles were excluded because of either non-relevant content or publication type. The total set of articles was then reviewed against previously identified research, as well as bibliography comparisons. Based on the results from the secondary review, 12 articles were added to the systematic review matrix. The added articles are noted in the matrix with an asterisk. A graphic display of the search methods in the PRIMSA format is found in Appendix A.
Lauren Johnson USF Health Design Center

RE: **Expedited Approval** for Initial Review IRB#: Pro00002291

Title: Parent Perspectives on Life with a Child with Diabetes

Dear Lauren Johnson:

On 10/7/2010 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol. Please note that your approval for this study will expire on 10/7/2011.

Approved Items: Protocol Document(s):

- **Protocol.docx** 9/17/2010 4:30 PM 0.03 Consent/Assent
- **ic-sb-minimal-3.doc.pdf** 10/7/2010 4:49 PM 0.01

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Krista Kutash, Ph.D., Chairperson USF Institutional Review Board

Cc: Olivia Hart, USF IRB Staff
Appendix D: USF IRB Informed Consent

Informed Consent to Participate in Research
Information to Consider Before Taking Part in this Research Study

IRB Study # 00002291

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study.

We are asking you to take part in a research study that is called: Parent Perceptions on Life with a Child with Diabetes

The person who is in charge of this research study is L. Nicole Johnson. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge.

The person explaining the research to you may be someone other than the Principal Investigator. Other research personnel who you may be involved with include: Dr. Carol Bryant.

The research will be done at The University of South Florida campuses.

Purpose of the study
The purpose of this study is to gain feedback from parents of adolescents with Type 1 Diabetes to understand their perceptions of living with diabetes. Information from this research may guide product and program development that could improve the education, health and wellbeing of children and families with diabetes.

Study Procedures
If you take part in this study, you will be asked to:
Participate in either a focus group or individual interview depending on their availability.
Focus groups and individual interviews should take about an hour.
All interviews and focus groups will be audio recorded. All recordings and transcripts will be kept in a locked location in the Bringing Science Home offices.
Tapes will be destroyed upon transcript completion.

Alternatives
You have the alternative to choose not to participate in this research study.
Benefits

We don’t know if you will get any benefits by taking part in this study.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You will be given a $10 gas card for travel time and refreshments if you participate in either the interview or a focus group. Refreshments will include a light/healthy snack and water or diet soda.

The findings from this research may result in the future development of products that are of commercial value. There are no plans to provide you with financial compensation or for you to share in any profits if this should occur.

Conflict of Interest Statement

There are no conflicts of interest for study investigators.

Confidentiality

We must keep your study records as confidential as possible

- Tapes will be kept until transcripts are created and approved.
- Transcripts will be kept for 5 years.
- Transcripts will be kept secure, private and in a locked location until disposal.
- If they will be shown to “any other professionals” or used in any other research.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, study coordinator, research nurses, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.) These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
The Department of Health and Human Services (DHHS).

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time.

Questions, Concerns, or Complaints

If you have any questions, concerns or complaints about this study, call Nicole Johnson at 813-396-2683.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-5638.

If you experience an unanticipated problem related to the research call Nicole Johnson at 813-396-2683.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study          Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

• What the study is about.
• What procedures/interventions/investigational drugs or devices will be used.
• What the potential benefits might be.
• What the known risks might be.
Signature of Person Obtaining Informed Consent  Date

Printed Name of Person Obtaining Informed Consent
Appendix E: Focus Group / Interview Questions

Focus Group / Interview Questions:

- When I say diabetes, what is the first thing that comes to mind?
- How has diabetes affected your life as a parent?
- What are some of the greatest challenges you face now in helping your child manage diabetes?
- What worries you most?
- Can you talk a little about your role in helping your child manage diabetes? What do you typically do? What does s/he do well? What does s/he do poorly?
- If a friend told you him/her child were just diagnosed with diabetes, what advice would you give him/her? Where would you refer her for health information and medical support?
- Where do you go for that type of help?
- Do you feel your needs as a parent have been acknowledged and addressed by your diabetes health team?
- What advice would you give parents about how to cope with having a child with diabetes?
- Do you feel there is distress in your family related to diabetes?
- Where is the distress coming from?
- Imagine you are on an advisory group that can design a program for parents like you……what could this program do to help?
Appendix F: Qualitative Analysis Preliminary Codebook

<table>
<thead>
<tr>
<th>A PRIORI CODES</th>
<th>EMERGENT CODES</th>
<th>DESCRIPTIVE INFO FROM TRANSCRIPTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional / Psychological</td>
<td>Denial:</td>
<td>Lack of acceptance, not recognizing disease</td>
</tr>
<tr>
<td></td>
<td>Fear:</td>
<td>Scary feelings, worry about child’s future, complications</td>
</tr>
<tr>
<td></td>
<td>Frustration:</td>
<td>System frustration, management of disease, lack of info</td>
</tr>
<tr>
<td></td>
<td>Negativity:</td>
<td>Around disease too much, support groups, negative people</td>
</tr>
<tr>
<td></td>
<td>Emotional Release:</td>
<td>Crying, parent emotions</td>
</tr>
<tr>
<td></td>
<td>Self-sacrifice:</td>
<td>Focusing only on child needs</td>
</tr>
<tr>
<td></td>
<td>Sadness:</td>
<td>Overwhelming, grief, crying</td>
</tr>
<tr>
<td></td>
<td>Distress:</td>
<td>Family stress, stress on relationships, stress with health providers</td>
</tr>
<tr>
<td></td>
<td>Isolation:</td>
<td>Feeling alone, family isolation, individual isolation, self isolation</td>
</tr>
<tr>
<td>Material Needs</td>
<td>Cost:</td>
<td>Expense of diabetes, limited resources, cost of care</td>
</tr>
<tr>
<td></td>
<td>Safety:</td>
<td>Concerns about society, preparation, safety practices</td>
</tr>
<tr>
<td></td>
<td>Tools:</td>
<td>Ideas for what would make life better, things needed</td>
</tr>
<tr>
<td></td>
<td>Confusion:</td>
<td>Inaccurate information, not enough help, system navigation</td>
</tr>
<tr>
<td>Knowledge/People Needs</td>
<td>Community:</td>
<td>Support systems, organizations, family support</td>
</tr>
<tr>
<td></td>
<td>No support:</td>
<td>Lack of services and people support</td>
</tr>
<tr>
<td></td>
<td>Peers:</td>
<td>Friends and supporters, connections to others like you</td>
</tr>
<tr>
<td></td>
<td>Balance:</td>
<td>Balance for family, for siblings, balance involvement in care</td>
</tr>
<tr>
<td></td>
<td>Guilt:</td>
<td>Emotional response to non-diabetic family needs and personal needs</td>
</tr>
<tr>
<td>Obstacles / Challenges</td>
<td>Knowledge:</td>
<td>Lack of knowledge, knowledge as power, education</td>
</tr>
<tr>
<td></td>
<td>Control:</td>
<td>Diabetes management, glucose numbers</td>
</tr>
<tr>
<td></td>
<td>Ignorance:</td>
<td>Not aware of what diabetes is, lack of info available</td>
</tr>
</tbody>
</table>
Appendix G: Qualitative Study Flyer

Parent Perspectives on Life with a Child with Diabetes

Bringing Science Home is recruiting parents who have a child or young adult with Type 1 Diabetes to participate in a research study.

This research study is designed to gain feedback from parents of children and youth with Type 1 Diabetes to understand their perceptions of living with diabetes and their needs as parents. Information from this research will guide product and program development.

We are seeking participants for focus groups and interviews.

If you are interested in participating, please contact Nicole Johnson or Stephanie Melton at BringingScienceHome@gmail.com or 813-396-2677.

The mission of Bringing Science Home is to empower people touched by chronic disease to live optimistically and to create a new model for chronic disease education and care. Bringing Science Home is funded by the generosity of The Patterson Foundation.

www.BringingScienceHome.com
Appendix H: Pilot PDDS Ethical & Independent Review Services Document

Dear Dr. Polonsky:

Using the exemption review process, the E&I administrative review team has accepted your study in accordance with 45 CFR 46.101(b)(2). Please keep this approval document with your study records.

- E&I is making a determination that the study qualifies for an exemption from the need for IRB review.
- This determination does not include review of a consent process or form or of the research itself.
- Researchers are advised that they should adopt the principles in The Belmont Report or an appropriate ethical code in the conduct of their studies.
- Researchers are advised to maintain excellent communication with sites/school authorities.
- All researchers must comply with relevant state and federal regulations.

<table>
<thead>
<tr>
<th>E&amp;I Assigned Study ID: 12172 - 01</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Certification: September 25, 2012</td>
</tr>
<tr>
<td>Date of Check-In: September 24, 2013</td>
</tr>
</tbody>
</table>

Minimum Responsibilities of the Research Team:

1. Report any protocol violations, and or serious and related unanticipated problems involving risks to your subjects or others in a timely manner.
2. Submit any desired modifications for review and consideration prior to carrying out such changes.
3. Submit an update of your study activities before the check-in date noted above.

Thank you for choosing E&I and please feel free to contact us anytime, we are here to help.

Sincerely,

Mona Bosch, CIP
E&I Administrative Review Team
Appendix I: Parent Diabetes Distress Scale Battery of Questionnaires

DEMOGRAPHICS

1. About your teen with diabetes:
   a. Your teen’s age in years
   b. Your teen’s gender?
   c. Your teen’s current grade level in school:
   d. How old was your teen when first diagnosed?
   e. What is your teen’s current insulin delivery system: vial and syringe, pen or pump?
   f. What is your teen’s most recent HbA1c (blood test that measures average blood sugar level):
      ____%
      ____No test has occurred in the past year
      ____I don’t know
   g. What did your teen’s doctor tell you about what your teen’s HbA1c level should be?
      ____%
      ____I don’t know
   h. What is your HbA1c goal for your teen?
      ____%
      ____I don’t have a different HbA1c goal
   i. How many severe low blood sugar episodes in the past year has your teen had? (“severe” means an episode that required help from another person)
      ____
      ____I don’t know
   j. How many days of school in the past month did your teen miss because of diabetes.
      ____
      ____I don’t know
   k. In your estimation, how worried is your teen about hypoglycemia?
      ____Not worried at all
      ____A little worried
      ____Moderately worried
      ____Extremely worried

2. Have you been told that your teen has been diagnosed with any of the following?
   a. Depression
      ____yes ____no ____not sure
   b. Attention-deficit hyperactivity disorder (ADHD)
      ____yes ____no ____not sure
   c. Anxiety disorder
      ____yes ____no ____not sure
   d. Schizophrenia, or other psychotic disorder
      ____yes ____no ____not sure
   e. Intellectual disability (mental retardation)
      ____yes ____no ____not sure
   f. Eating disorder
      ____yes ____no ____not sure
3. About you:
   a. What is your age (in years)? _____years
   b. Are you married, divorced, widowed, single? (check one)
   c. Are you currently living with:
      ___ your teen’s other biological parent?
      ___ a different partner?
      ___ no partner at present
   d. What is your gender?
   e. Are you the biological parent, step-parent or other of your teen?

4. About the people who live in your home:
   a. How many other children in the home, and what are their ages?
   b. Does your teen live with you full-time, part-time, or not at all?
   c. Do you currently live with a spouse or partner? If, yes, is this person your
      teen’s other biological parent?
   d. Does your teen’s other biological parent live with the teen full-time, part-time,
      or not at all?

5. In the past year, have you been diagnosed or treated for:
   a. Depression _____yes ___no ___not sure
   b. Anxiety disorder _____yes ___no ___not sure
   c. Alcohol or substance use or addiction _____yes ___no ___not sure
The following questions ask about how you have been feeling as a parent of a teen with diabetes. For each item, circle the number that gives the best answer for you. Please provide an answer for each question.

During the past month, I have been:

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling unclear about exactly how much I should be involved in managing my teen’s diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Worrying that diabetes will make it hard for my teen to have a happy life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Concerned that I nag my teen too much.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Feeling that my teen doesn’t try hard enough to manage his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
</tr>
<tr>
<td>5. Worrying that my teen will develop serious complications from diabetes in the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Depressed about my teen's diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Feeling that I stay silent about my teen's diabetes more than I really should.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
</tr>
<tr>
<td>8. Feeling unappreciated for all the ways I try to help my teen manage diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
</tr>
<tr>
<td>9. Feeling overwhelmed by the constant demands of my teen’s diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td></td>
<td>10. Worrying about my teen’s low blood sugars when he/she is away from home.</td>
<td>Not at all</td>
<td>A little</td>
<td>Somewhat</td>
<td>A lot</td>
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<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td></td>
<td>11. Aggravated with my teen about his/her management of diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td></td>
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<td>0</td>
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<td></td>
<td>12. Feeling that I don't know enough about how to help my teen manage diabetes more successfully.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>13. Worrying that diabetes is taking up too much of my teen’s mental and physical energy every day.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>14. Feeling that diabetes is taking up too much of my mental and physical energy every day.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>15. Feeling that no one notices that diabetes is hard on me, not just on my teen.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>16. Feeling &quot;burned out&quot; that I never get a break from worrying about my teen’s diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>17. Stressed out that I often can’t tell the difference between mood swings that are diabetes-related vs normal teen-related.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td></td>
<td>18. Feeling that my teen and I just don’t work well together when it comes to diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>19. Worrying about my teen’s high blood sugars.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td></td>
<td>20. Feeling that I can’t trust my teen to take good care of his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td></td>
<td>Not at all</td>
<td>A little</td>
<td>Somewhat</td>
<td>A lot</td>
<td>A great deal</td>
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<tr>
<td>21. Worrying that others will blame me if my teen’s diabetes is not well-controlled.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. Frustrated that the more I try to help my teen manage his/her diabetes, the worse things get between us.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. Frustrated by the lack of understanding and support for diabetes I get from friends and family members.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Frustrated by the lack of support about diabetes from school and teachers.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>25. Worrying that my teen doesn’t have the right doctor for him/her.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. Feeling guilty about not doing enough to help my teen with diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. Frustrated that I can’t get my teen to improve his/her attitude about diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. Frustrated that I am the only one who takes responsibility for helping my teen manage diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>29. Worrying that I am failing to help my teen successfully manage diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>30. Afraid that there is no one else to help my teen with his/her diabetes if I am not around.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
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<tr>
<td>31. Worrying that my teen will ignore or forget diabetes if I don’t keep reminding him/her.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>32. Feeling that trying to help my teen with his/her diabetes is always a battle.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td></td>
<td>Not at all</td>
<td>A little</td>
<td>Somewhat</td>
<td>A lot</td>
<td>A great deal</td>
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<tr>
<td>33. Frustrated that I cannot get my teen to follow through on what needs to be done with diabetes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. Worrying that I have little control over how my teen manages his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. Feeling that my teen doesn’t do enough to manage his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36. Frustrated because my teen ignores my suggestions about diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37. Worrying that my teen doesn’t get all of the expert medical help he/she needs.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>38. Feeling uncertain about how to motivate my teen to take better care of his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
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<tr>
<td>39. Worrying that my teen does not know how to manage diabetes properly when a responsible adult is not around.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>40. Worrying that my nagging about diabetes is hurting my relationship with my teen.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>41. Worrying that my teen will soon leave home and I cannot protect him.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42. Feeling guilty that I am looking forward to my teen leaving home after high school.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43. Frustrated that my teen is always “forgetting” his/her diabetes supplies.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44. Stressed out about when and how to allow my teen more responsibility for his/her diabetes.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Not at all</td>
<td>A little</td>
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<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>A great deal</th>
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<td>0</td>
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</tbody>
</table>

During the last month, how confident have you been about:

<table>
<thead>
<tr>
<th>Not confident at all</th>
<th>A little confident</th>
<th>Somewhat confident</th>
<th>Very confident</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Not confident at all</th>
<th>A little confident</th>
<th>Somewhat confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>

During the last month, how satisfied or dissatisfied have you been regarding your teen’s diabetes management?

<table>
<thead>
<tr>
<th>How satisfied have you been with:</th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Not satisfied or dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often your teen tests?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. How well your teen is taking insulin as required?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. How well your teen is following a diabetes-friendly way of eating?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
4. How well your teen is managing diabetes overall?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
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</table>

For each statement, please circle the number that describes your beliefs about parenting your child. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Somewhat</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When I ask my teen to do something, I expect it to be done immediately without questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I do not allow my teen to question the decisions that I make.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I get very upset if my teen tries to disagree with me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I tell my teen what he/she should do, but I explain why I want them to do it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I expect my teen to follow my directions, but I am always willing to listen to their concerns and discuss the rules with them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. If I make a decision that hurts my teen, I am willing to admit that I made a mistake.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Somewhat</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>-------</td>
<td>----------</td>
<td>----------</td>
<td>-------------------</td>
</tr>
<tr>
<td>7. My teen needs to be free to make his/her own decision, even if this disagrees with what I might want to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Most of the time I do what my teen wants when making decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Most problems in society would be solved if parents would let their teens choose their activities, make their own decisions and follow their own desires when growing up.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Over the past month, how much emotional support have you personally received from others regarding your coping with diabetes and your teen?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. From friends and family members</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. From health care professionals</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. From other parents who have teens with diabetes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Somewhat</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>----------------</td>
<td>-------</td>
<td>----------</td>
<td>----------</td>
<td>-------------------</td>
</tr>
<tr>
<td>4. From support groups, live or online</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. From professional organizations like JDRF or CWD</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Over the past month, separate from any problems you may be having with diabetes and your teen, please rate your current level of general life stress in the following areas.

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Financial problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Work-related problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Marital or other relationship problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Other family problems (for example, regarding other children, parents or siblings)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Other health problems (your own, or in other family members)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
For each statement below, please circle the number that describes your current beliefs about your teen’s diabetes.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Somewhat</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When my teen’s blood sugars are high, it is almost always because he/she isn’t trying hard enough.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. If I don’t keep reminding my teen about checking blood sugars and other diabetes-related tasks, he/she will probably stop doing them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. It is important that I frequently remind my teen that terrible things will happen if he/she doesn’t start taking better care of his/her diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. My teen should be fully responsible for taking care of his/her own diabetes now, so that she/he will be able to manage later as an adult.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. When I discover that my teen is not managing diabetes well, the most important thing I can do is punish him/her.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. I don’t bother my teen much about how to manage diabetes, since just having this disease is tough enough for him/her already.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. To avoid blood sugar problems, it is important that I limit my teen’s independent activities (for example, sleepovers).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I am failing as a parent if my teen’s blood sugars are not tightly controlled.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. If my teen cannot avoid almost all high blood sugar readings, then he is certain to develop serious complications.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
10. It is important that my teen fully understand and appreciate that neglecting diabetes will hurt his/her future health.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Somewhat</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Please complete the following scale ONLY if you share responsibility for your teen’s diabetes with a spouse/partner. (If not, skip to questions #XX).

Over the past month:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often do you and your spouse/partner disagree on how to manage your teen with diabetes?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. When you and your spouse/partner have a disagreement about your teen’s diabetes, how often do you find that you are arguing again later about the same thing?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. When you have a disagreement with your spouse/partner about diabetes, how often do you remain angry or bothered with your spouse/partner for a long time?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Over the last 2 weeks, how often have you been bothered by any of the following problems? Circle the best number.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself- or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed. Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

9. If you checked off any of the above problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? Circle One.

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Not difficult at all</th>
<th>Somewhat difficult</th>
<th>Very difficult</th>
<th>Extremely difficult</th>
</tr>
</thead>
</table>

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
ABOUT THE AUTHOR

Lauren Nicole Johnson received her MPH from the University of Pittsburgh in 2007 and her MA in Journalism from Regent University in 1998. She has lived with Type 1 diabetes since 1993. Diabetes lead her to public health and in 2009, she joined USF Health professionally. She has served as the Executive Director of Bringing Science Home (BSH) at USF Health since 2010. Johnson secured the funding for BSH and utilizes the opportunity to manage the program to infuse creative thought into diabetes research nationwide.

Johnson has served on numerous advisory boards in her career in diabetes. She served the National Institutes of Health as an appointee to the Council of Public Representatives from 2004-2008, is a past national Board Member for the American Diabetes Association, and is a two-time appointee to the Florida Governor’s Diabetes Advisory Council. Johnson also served as an appointee to the Pennsylvania Governor’s Council for Physical Fitness and Sports.

In 2012, Johnson joined the International Board of Directors for JDRF, a premier international research institution and is playing a key role in leading JDRF’s consideration of psychosocial issues in research. In 2013, Johnson was appointed to JDRF’s International Board of Directors Executive Committee. Johnson also serves on the Tampa Bay JDRF Board of Directors.

Johnson is perhaps most well known as Miss America 1999, a year in which she served the diabetes community as an educator, motivational speaker, author, and fundraiser. A year that also lead her to Public Health.

Johnson lives in Tampa, FL with her daughter.