THE ROLE OF CERTIFIED CHILD LIFE SPECIALISTS IN HELPING CHILDREN COPE WITH THE STRESS OF DIABETES

by

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ABSTRACT

Diabetes is a significant health issue in the United States. Living with diabetes can be very stressful for children and adolescents. As such, children with diabetes may need support from medical professionals, and to be taught ways to cope with the stress of their illness. A Certified Child Life Specialist (CCLS) is a member of the pediatric health care team whose job is to respond to the psychosocial needs of children and help them cope. The goal of the present study was to determine what role CCLSs may play in the management of pediatric diabetes.

Data were collected at the Diabetes Clinic at Primary Children's Hospital from parents of children ages 5+ years, and children and adolescents 10+ years. Participants completed questionnaires addressing demographic information, the stress children with diabetes were experiencing, how much help with coping pediatric diabetes patients and their families desired, and the services they would like to receive.

The majority of children needed help coping with their diabetes. Most parents did not know about the role of a CCLS before taking the survey, and there was a gap between the child life services families desired and those they received.

The results of this study indicate that most children need at least some assistance coping with stress associated with their diabetes. Due to the fact that the majority of parents did not know about CCLSs, greater awareness of the profession

needs to be promoted. Gaps existed for all of the child life services, with services being desired that were not being received. This gap provides an opportunity for CCLSs to address the need for services.

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INTRODUCTION

The purpose of this research was to determine what role Certified Child Life Specialists (CCLSs) may play in the management of pediatric diabetes. This includes assessing the levels of stress experienced by children with diabetes, how much help coping they need, and what child life services they and their families would like access to.

Diabetes mellitus (DM) is a serious problem in the United States that affects a significant number of children and adolescents, and is different from other chronic illnesses in that it requires constant monitoring throughout the day (Wiebe, Berg, & Helgeson, 2016). Research suggests that living with diabetes can be very stressful for children and adolescents, and that this stress can lead to both psychosocial challenges and negative health outcomes (Davidson, Penney, Muller, & Grey, 2004; Farrell, Hains, Davies, Smith, & Parton, 2004; Freeborn, Dyches, Roper, & Mandleco, 2013; Hauser et al., 1997; Seiffge-Krenke, 1998; Stabler et al., 1987). Research has also shown that improved metabolic control and diabetes life satisfaction are linked to actively and effectively coping with the stress that DM causes (Graue, Wentzel-Larsen, Bru, Hanestad, & Søvik, 2004). As such, the fostering of diabetes-related coping skills in childhood has the potential to impact children's success in DM management and psychosocial outcomes.

Previous studies have suggested that youth with diabetes may need

additional psychological support to deal with managing their disease and coping with the stressors associated with it (Davidson et al., 2004; Freeborn et al., 2013). One potential additional source of support in the healthcare setting is the CCLS, who specializes in helping children and adolescents foster healthy coping strategies. Although some studies have looked at the role CCLSs play in helping children cope (Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006; Carson, Jenkins, & Stout, 1985; Gursky, Kestler, & Lewis, 2010; Wolfer, Gaynard, Goldberger, Laidley, & Thompson, 1998), the current research is unique in focusing directly on children and adolescents with diabetes.

Diabetes in Childhood

DM refers to a group of metabolic conditions characterized by hyperglycemia (American Diabetes Association, 2013a), which is the result of defects in insulin secretion, insulin action, or both. Depending on the cause of pathology, DM is most commonly diagnosed as Type 1 or Type 2 diabetes. Type 1, historically known as insulin-dependent diabetes or juvenile-onset diabetes, is the result of a lack of insulin secretion, or more specifically "a cellular-mediated autoimmune destruction of the β-cells of the pancreas" (American Diabetes Association, 2013a, p. S67-S68). Type 2, commonly known as noninsulin dependent diabetes or adult-onset diabetes, "is a combination of resistance to insulin action and an inadequate compensatory insulin secretory response" (American Diabetes Association, 2013a, p. S67). Once a person has diabetes, they will always have it.

Type 1 diabetes is the most common severe chronic disorder of childhood,

affecting 1 in every 400 individuals under the age of 20 (Ambrosino et al., 2008). In 2012 about 208,000 Americans under the age of 20 had been diagnosed with DM, accounting for approximately 0.25% of that age group (American Diabetes Association, 2016). Not only is this number of children being diagnosed with DM high, but it is also drastically increasing (National Diabetes Education Program, 2014). As such, it is reasonable to assume that more and more children across the United States are seeking medical attention to help them manage their diabetes.

Diabetes is different from other chronic illnesses in that it requires constant monitoring throughout the day, which can be very stressful for children and adolescents to have to manage (Wiebe et al., 2016). Monitoring one's diabetes typically includes checking blood sugar levels multiple times every day and regularly attending doctor appointments. Along with monitoring, living with diabetes can require certain lifestyle changes (Beveridge, Berg, Wiebe, & Palmer, 2006). This can mean taking insulin and/or medications, diet modification, and increasing exercise. Due to the fact that diabetes is a life-long illness, individuals with this disease must always think about it and the consequences that can result if it's not managed. Not monitoring one's diabetes can lead to a multitude of very serious, life-threatening conditions.

As previously stated, individuals with diabetes have to monitor their illness very closely in order to prevent severe consequences from occurring. The conditions that can result from uncontrolled diabetes include long-term damage, dysfunction, and failure of vital organs – including the eyes, kidneys, and heart (American Diabetes Association, 2013a). Individuals with uncontrolled DM may

develop potentially lethal conditions such as ketoacidosis or nonketotic hyperosmolar syndrome (American Diabetes Association, 2013a) that can result in a coma or death (American Diabetes Association, 2015, 2013b). According to the American Diabetes Association (2013a), individuals with DM can experience a loss of vision; renal failure; a risk of foot ulcers; amputations; Charcot joints; gastrointestinal, genitourinary, and cardiovascular symptoms; and sexual dysfunction.

Stress of Living With Diabetes

Given the serious nature of diabetes, the fact it is lifelong, requires constant monitoring, and can potentially lead to very serious complications, it is not surprising that all of this can be very stressful, particularly for children and adolescents (Beveridge et al., 2006; Freeborn et al., 2013; Hema et al., 2009).

A study by Freeborn, Dyches, Roper, and Mandelco (2013) provided findings that allow us to better understand the challenges children face when managing Type 1 diabetes. The goal of the research was to identify from their own perspectives the challenges children and adolescents with Type 1 diabetes were experiencing. The researchers used a qualitative descriptive design using focus groups to determine the participants' challenges. Six focus groups were held over a 4-month period, with each participant attending 1 focus group. A total of 16 children and adolescents with Type 1 diabetes participated in the study. After analyzing the transcripts from the focus groups, three themes emerged as challenges the children and adolescents with Type 1 diabetes were facing.

The first stressor participants identified was managing low blood glucose. The study showed that checking blood glucose and administering insulin could interfere with normal childhood activities, and make children with diabetes feel separate from their peers. Feeling like they couldn't participate in activities with their peers because of their diabetes caused these children to feel stressed. The second stressor participants identified was self-care activities, including checking blood glucose and administering insulin. They revealed that this was an everyday trial due to pain and inconvenience. The third stressor participants identified was feeling different and/or alone. They revealed that their teachers and peers often singled them out for their diabetes. Results from the study indicated that spending time with other children and adolescents with Type 1 diabetes could help address the stress caused by feeling different and/or alone from their peers. The study also concluded that it is very important for health care professionals to help children and adolescents find ways to cope with the previously mentioned stressors caused by their disease in order to promote healthy outcomes (Freeborn et al., 2013).

A study by Davidson, Penney, Muller, and Gray (2004) reported challenges faced by adolescents with Type 1 diabetes that are very consistent with the findings from Freeborn et al. (2013). The goal of the research was to describe stressors and self-care challenges reported by adolescents with Type 1 diabetes. The researchers used a qualitative study design with 34 participants between the ages of 12 and 20 years old. Data were collected and analyzed from about 15 hours of interaction where the teens communicated their experiences with diabetes.

Adolescents in the study described diabetes as being difficult, demanding,

and never ending. One challenge participants reported was disease management. Having trouble being consistent with their care, managing its complexity, and feeling guilty about "bad numbers" were common themes among the participants. Some other challenges the teens communicated were based on relationship issues. All of the participants were concerned about how their diabetes impacted their relationships with peers, parents, and healthcare professionals, as well as their self-identity, and social opportunities. Lastly, participants reported struggling with situational stressors. The teens felt that when they were home their diabetes was much more manageable than when they were outside of their home. Overall, the results from the study indicated that the teens had a hard time balancing the stressors that came from being an adolescent and the stressors that came from having diabetes. Participants felt that it was hard to cope with all of the stressors they were experiencing.

Given the challenges associated with diabetes and the stress it can cause, it's important to recognize that such stress can lead not only to psychosocial challenges, but also to negative health outcomes. For example, higher levels of diabetes-related stress have been associated with poorer blood glucose control (Farrell et al., 2004). In a study by Farrell, Hains, Davies, Smith, and Parton (2004), youth cognitive distortions (having a negative perception of one's body and/or situation) were found to have an effect on both diabetes-specific and general stress. The more distortions an individual had, the more stress they reported. Diabetes-related stress was found to have a direct effect on an adolescent's blood glucose control, while general stress indirectly affected it. Even minor, everyday stressors were shown to

have a negative impact on the adolescent's immune and circulatory systems, and raise their blood sugar levels (Hauser et al., 1997; Seiffge-Krenke, 1998; Stabler et al., 1987).

Coping With Diabetes

Children and adolescents with diabetes need ways to manage the stress they feel in order to prevent that stress from having a negative impact on their mental, social, and physical health. The process of managing stressors (internal and external demands) has been referred to as coping (Lazarus & Launier, 1978). Research has shown that in adolescents with Type 1 diabetes, active coping, defined as taking direct action to get around the stressor, is related to improved metabolic control and diabetes life satisfaction (Graue et al., 2004). Examples of active coping might include concentrating efforts on doing something about it, removing the stressor, and doing what has to be done, one step at a time. Approaches to coping with diabetes are likely developmental in nature. More specifically, the older a child gets the better they can cope, with adolescents using more active coping with Type 1 diabetes compared to younger children (Hema et al., 2009; Landolt, Vollrath, & Ribi, 2002; Seiffge-Krenke & Stemmler, 2003). Research by Grey, Boland, Davidson, Li and Tamborlane (2000) found that adolescents who received coping skills training (by a qualified nurse practitioner with experience in pediatric psychiatry and diabetes) as well as intensive diabetes management (3 or more daily injections, monthly outpatient visits, and interim telephone contacts), experienced a faster and greater decline in HbA1c (a form of hemoglobin that is bound to glucose)

concentrations after 6 and 12 months. The greatest improvement, however, was in quality of life, which occurred during the first 3 months of the intervention, and lasted throughout the 12-month study. The researchers found that the coping skills training and diabetes management together increased the adolescent's sense of capability in dealing with diabetes-specific situations, as well as other medical situations.

Managing diabetes requires constant monitoring, and is often difficult for children and adolescents. At least two published studies have shown that children with diabetes need support and education from family members and healthcare professionals in order to successfully manage their illness and cope with the stress it can cause (Weinzimer, Doyle, & Tamborlane, 2005; Wiebe et al., 2016). Previous research has demonstrated that the formation of DM-related coping skills in childhood can ultimately impact a child's success in DM management and psychosocial outcomes. Interventions focusing on age and developmentally appropriate skill obtainment in the areas of self-efficacy, metabolic control, and active coping may mitigate the impact of diabetes on a child's quality of life.

The results of Davidson et al. (2004) and Freeborn et al. (2013) suggest that youth with diabetes may need additional psychological support to deal with managing the disease and the stressors associated with the disease. The management of diabetes requires a positive support system. "Warm, supportive, and collaborative relationships" have been found to help with diabetes management (Wiebe et al., 2016, p. 534). One potential source of support, and this kind of relationship in the health care setting, is offered by the CCLS, who is an important

part of the health care team. As such, becoming informed about the specific challenges and stressors children with diabetes are facing can help CCLSs develop interventions for these children that will be both positive and beneficial. Their efforts can have an influential impact in providing coping skill formation for these children.

Certified Child Life Specialists

CCLSs are members of the pediatric health care team (Cole, Diener, Wright, & Gaynard, 2001), who work to support ill children and their families in order to help them develop a sense of control and ultimately gain cooperation with their medical care (Tamiya, 2003). They are trained with a background in child development and families (Child Life Council, 2015) and specialize in "coping through play, preparation, education, and self-expression activities" (Child Life Council, 2015, n.p.). The job of a CCLS was created to respond to the psychosocial needs of children in medical settings (Cole et al., 2001). Research has shown that across development, family members are the most influential sources of support, and have been consistently associated with good health outcomes (Berg et al., 2007; Wiebe et al., 2016). CCLSs recognize the family as the essential unit in supporting the child's health, and include the family in the care provided (Child Life Council, 2002; Cole et al., 2001; Ghetti, 2011; Parvin & Dickinson, 2010; Smith, Desai, Sira, & Engelke, 2014). Thus, in addition to helping the young patient understand what is happening in the healthcare setting, the CCLS helps the family to understand what the patient is going through and how to cope with the range of emotions family members are

likely to experience (Cole et al., 2001). CCLSs also play an important role in advocating for the patient's and their family's needs, providing education and support for siblings, and encouraging and strengthening caregivers (Ghetti, 2011; Smith et al., 2014). The American Academy of Pediatrics (2006) recommends that child life services be considered an essential aspect of quality pediatric healthcare.

One of the most important roles of CCLSs is to help children cope with stressful healthcare experiences (Ghetti, 2011). CCLSs have been shown to use a variety of coping strategies in order to help reduce children's distress during painful medical interventions. Survey results showed that the most effective and frequently used strategies for providing pain management in general are: supplying information, preparation, positive reinforcement, behavioral distraction, and comfort positioning (Bandstra et al., 2008). Providing coping strategies for siblings and other family members is also part of the child life profession (Smith et al., 2014). Due to their specialization in coping, CCLSs could potentially be very valuable in helping youth manage the stress of their diabetes.

Current Study

The current study addressed several research questions: How stressed are children with diabetes, and how is age related to this stress? How much help do children need coping with this stress? Does a gap exist between child life services wanted and child life services being received?

First, we examined what challenges children and adolescents diagnosed with DM are currently facing. Then we examined how much help they needed coping

with their chronic illness. We also determined what child life services these children and adolescents were already receiving, and what services they and their parents would like to receive. Although some studies have looked at the role of CCLSs in helping children cope (Brewer et al., 2006; Carson et al., 1985; Gursky et al., 2010; Wolfer et al., 1998), the current study focused directly on children and adolescents with diabetes, thus the ultimate purpose of our study was to determine what role CCLSs may play in the management of pediatric DM.

METHOD

Participants

Participants were parents of children with diabetes (5 years old and older), and youth (10 years old and older) receiving treatment at Primary Children's Diabetes Clinic. One hundred and thirty four youth and 166 parents were approached at the outpatient diabetes clinic at Primary Children's Hospital, and 124 youth and 157 parents agreed to participate, yielding 93% and 95% response rates, respectively.

Children ranged in age from to 5 to 18 years of age; 66% were 13 years old or younger, M = 11.87 years, SD = 3.45 months. Fifty-five percent were male. The majority of participants were Caucasian. The age of diagnosis ranged from 1 to 18 years old. The age of diagnosis was M = 7.56 years, SD = 3.86 months. The number of diabetes-related emergency room visits ranged from 0 to 10, with 92% having 3 visits or fewer. Ninety-nine percent of the sample had Type 1 diabetes, and 1% had Type 2 diabetes. For those who completed the parent survey, 82% were mothers and 15% were fathers. The remaining 3% were either grandparents, or checked an "other" category. Forty-three percent of the sample had completed some college, and 39% had earned a college degree or more. The remaining eighteen percent had earned a high school degree or less.

Procedure

Parents of patients 5 years old and older attending the Diabetes Clinic at Primary Children's Hospital were approached in the clinic by 1 of 6 research assistants trained specifically for the purposes of this project and invited to complete a survey. Their children receiving treatment at the clinic were also asked to complete a survey if they were 10 years old or older. Researchers provided hard copies of the surveys after consenting the participants, and were available to answer questions. If parents or the children/adolescents were unable to complete the survey during their clinic visit, they were given a stamped, self-addressed envelope to mail the survey back. However, efforts were made to obtain completed surveys during the office visit while they were waiting for the doctor.

Participants were given the option to enter their name into an opportunity drawing for $50 cash after completing the survey. We drew a name after every 20 participants completed the survey. We had separate drawings for children and parents.

Measures

Paper surveys were administered to participants (See Appendix A). Surveys included Likert-type scales and close-ended questions. The questions were aimed at identifying what challenges children and adolescents are currently facing, what techniques they use to cope with these challenges, psychosocial support services they're already receiving, and what services they would like to receive according to parents. Child surveys included questions about demographic information,

stressors, and coping. Parent surveys included questions about demographic information, stressors, coping, and child life services they were receiving or would like to receive.

Surveys were based on preexisting measures. We pilot-tested these surveys and revised them according to feedback from multiple people, including staff at Primary Children's Diabetes Clinic, parents of children with diabetes, young adults who were diagnosed with diabetes at a young age, a CCLS, research assistants, and other faculty members at the University of Utah. The survey is described in more detail below.

Demographic Information. The following demographic information was collected from parents and children/adolescents: child/adolescent's age/birthdate, gender, age when diagnosed with diabetes, race, the highest level of education completed by the parent, what type of diabetes the child had, and how many times the child has visited the emergency room for diabetes-related problems.

Stressors. The following information on stressors was collected from parents and children/adolescents. Questions were adapted from *Responses to Stress Questionnaire (RSQ)* from Compas (2000). For the child/adolescent survey we replaced the word stressor with things that are "hard" and "challenges" in order for the items to be easier to understand. This section consisted of ten items regarding specific stressors children with diabetes might experience, including feeling different from other kids, dealing with diabetes care, feeling guilty or upset about "bad numbers," not knowing how or if to tell others about their diabetes, others asking about their pump/injections/monitor, parents bugging them to take care of

themselves, going to clinic often and missing school, seeing their family worry about them, teachers/coaches/nurses/peers at school don't understand their diabetes, and having diabetes get in the way of their personal goals. Items were rated on a 3-point Likert-type scale, measuring how stressful each item was for the child (i.e. never stressful, sometimes stressful, and stressful a lot of the time). Items were averaged to create a composite stress score separately for the parent's and children's reports. Cronbach's alpha for each composite score, assessing the internal reliability of these measures, were alpha = .80 and .71 for children's and parents' measures, respectively. Both composite scores demonstrated adequate internal reliability.

Coping. The following information on coping was collected from parents and children/adolescents. Questions were adapted from *Children's Coping Questionnaire* by Fedorowicz (1995), and *The Children's Coping Behavior Questionnaire* by Hernandez (2008). For the child/adolescent survey, the word coping was replaced with "dealing" in order to make the items easier to understand. A question was asked about how often the child needed help dealing with these stressors now. This question was rated on a 3-point rating-type scale (i.e. never needs help, sometimes needs help, needs a lot of help).

Perceptions of Child Life. The following information on perceptions of child life was collected from parents. Questions were adapted from *Perceptions of the Role of Child Life Specialists* by Leblanc (2014). First, a brief description of what a CCLS is, and what role they play in the medical setting, was included. Participants were asked (check either yes or no) if they were aware of the role of a CCLS prior to

coming to Primary Children's Hospital. The next section consisted of seven questions regarding typical things child life specialists do when working with children. Items were rated on a 3-point Likert-type scale, asking about the specific service (i.e., Did your child need this service? Did your child receive this service? If so, how satisfied were you with this service?). Participants were directed to circle one answer for each question. The first two questions required yes or no responses, and the last one was answered with *very*, *somewhat*, or *not at all*.

RESULTS

Several sets of analyses were conducted examining different sets of questions. First, questions related to how much stress the children experienced according to the parent and child report were analyzed using descriptive statistics. Analyses of variance and correlations were used to analyze what factors were related to their stress level (e.g., child gender, child age, and management of diabetes). A correlation was used to measure the extent to which parents' reports of stress were associated with children's reports of stress. We used descriptive statistics to address how much help the parents perceive their children needed in coping with the stresses of diabetes. Descriptive statistics were used to find out how many participants knew about the role of a CCLS before taking the survey, and whether a gap existed between child life services desired relative to those being received.

How Much Stress Do Children and Adolescents Diagnosed With DM Experience?

We used descriptive statistics to find on average how much stress the children were experiencing. The percentage for how many children found each item to be stressful, as well as *M*s and *SD*s, are listed in Tables 1 and 2. For children's reports, the mean level of stress was 1.67 (*SD* = 0.35). Parents reported that their

children were experiencing stress levels similar to those the children reported, *M* = 1.74, *SD* = 0.39. Given these results, it appears children were experiencing low to moderate stress due to their diabetes.

We used a two-way analysis of variance to examine whether child gender was related to stress levels. We used the ratings of stressors as the dependent variable, and gender as the independent variable. Using the children's reports of stress, girls reported significantly more stress than boys, F (1, 115) = 7.15, p = .009, M = 1.75, SD = .33 for girls; M = 1.56, SD = .33 for boys. Child gender was not related to stress levels as reported by parents.

We also used a two-way analysis of variance to examine whether child age group was related to stress levels. We divided the participants equally into three age groups, younger than 10 years, 10-13 years, and older than 13 years. We used the ratings of stressors as the dependent variable, and age group as the independent variable. Age group was not significantly related to stress levels for the children's reports, F(2, 116) = .23, p = .80. For the parent reports, age group was significantly related to stress levels, F(2, 154) = 7.69, p<.001, indicating that parents perceived that older children were experiencing more stress than younger children (children older than 13 years showed more stress than children younger than 10 years, M = 1.83, SD = .43 for children over 13 years; M = 1.58, SD = .29 for those younger than 10 years).

Correlations were also conducted to examine the relationship between stress levels and age. These analyses were conducted separately for parents' and children's reports of stress. Consistent with the age group ANOVAs conducted

above, the analyses between child reported stress levels and child age indicated no significant correlation for the children's reports, $r(116) = -.03$, $p = .748$. Consistent with the analyses reported above, the correlation between parents' reports of children's stress levels and child age indicated that parents reported greater stress for older children, $r(155) = .26$, $p<.001$. Correlations were also used to measure associations between stress levels and diabetes management (as indicated by number of ER visits). The analyses were conducted separately for parent and children's reports of stress levels. The analyses indicated that diabetes management was not significantly related to children's reports of stress, $r(115) = .13$, $p = .175$. The analyses indicated that diabetes management was significantly correlated with parent reports of children's stress, $r(153) = .20$, $p = .012$. Parents reported that children who had more ER visits were more stressed by their diabetes.

We also used a correlation to measure the extent to which parent report of overall stress was associated with children's reports of stress. The results indicated that the parent report of stress was significantly correlated with the child report of stress, $r(115) = .46$, $p < .001$.

How Much Help Do Children Need Coping With This Stress?

First we used descriptive statistics to look at how much help the child needed with coping with the stress of diabetes (see Tables 3 & 4). Children reported that they needed some help coping with the stress of their diabetes, $M = 1.83$, $SD = .52$. Parents also reported that children needed some help coping with the stress of their diabetes, $M = 2.09$, $SD = .50$. Seventy one percent of children and adolescents said

they sometimes need help, and 6.3% said they need a lot of help. Seventy four percent of parents said their child sometimes needs help with coping, and 17.5% said their child needs a lot of help with coping.

To determine whether help coping was related to child age group, we used a Chi-Square Test. We used how much help they needed coping for the dependent variable, and child age group for the independent variable. For the children's reports, help coping was significantly related to child age groups, X^2 (4, N = 104) = 9.62, $p < .05$. Help coping was also significantly related to child age group for the parent reports, X^2 (4, N = 119) = 12.20, $p < .05$. These results indicate that the older children/adolescents were the more likely to never need help.

We also used a Chi-Square Test to see if help coping was related to child sex. We used how much help they need coping for the dependent variable, and child sex for the independent variable. Child sex was not significant for either the parent reports, X^2 (2, N = 119) = 4.89, $p = .09$, or the children's reports, X^2 (2, N = 104) = 9.53, $p = .62$.

We used a correlation to measure whether or not help coping was related to stress. The results indicated that all reports of stress were significantly related to how much help the children needed with coping, $r(112) = .39$, $p < .001$ for children's reports or stress and children's reports of coping, $r(91) = .42$, $p < .001$ for children's reports of stress and parent reports of coping, $r(120) = .48$, $p < .001$ for parent reports of stress and parent reports of coping, and $r(103) = .29$, $p < .005$ for parent reports of stress and children's reports of coping. This indicates that the more stressed the child was the more likely they were to need help coping.

What Child Life Services Are These Children and Adolescents Already Receiving, and What Services Would They and Their Parents Like to Receive?

The majority of parents surveyed (76.9%) did not know about the role of a child life specialist before taking the survey.

Table 5 shows which child life services parents indicated their children needed, whether they had received those services, and whether they were satisfied with the services they had received. We summed the total number of services they would like to receive to create a summary score, which was continuous. A higher score corresponded to a greater need. Just over half of participants surveyed said they needed at least 1 service, with the majority needing between 1 and 3 services.

Next, we examined whether there was a discrepancy between whether they said they needed a particular service and whether they have previously received that service. For all of the services there was a gap between the percentage of parents who reported that they needed the service and the percentage who reported that they had received the service. The biggest gaps existed for therapeutic dialogue, family facilitation, procedure support, and developmental support (see Figure 5). The majority of those that had received the service were satisfied with it.

To find whether child gender and child age group were related to services needed, we used repeated measures, two-way analysis of variance (ANOVA). We used services needed as the dependent variable, and child gender and child age group as the independent variables. Child gender was significantly related to

services needed, with girls having a higher need than boys, F (1, 154) = 4.45, p = .037. The main effect of child age group was not significant, however there was a gender and age interaction, indicating that younger females had an even greater need for services, F (2, 154) = 3.71, p = .03.

We used a correlation to compare the services they need with the length of time since they have been diagnosed. The length of time since diagnosis was not significantly related to any of the child life services r(154) = -.02, p = .84.

We used a correlation to examine the association between stress levels and how much help with the child desired with coping. The analyses were conducted separately for both the children's reports and parent reports for help desired. For the children's reports, help desired was significantly correlated with how stressed children reported they were, (112) = .39, p < .001. For the parent reports, help desired was also significantly correlated with how stressed they perceived the child to be r(120) = .48, p < .001. These results indicated that the more stressed the children and adolescents were, the more help they needed with coping.

Table 1

Children's Reports of Stress: Percentages and Means (SDs)

	Never stressful	Sometimes stressful	Stressful a lot of the time	M	SD
a. Feeling different from other kids	52.4	41.9	5.6	1.53	.60
b. Dealing with diabetes care (e.g., paying attention to what they eat, checking blood glucose, taking supplies wherever they go)	17.7	67.7	14.5	1.97	.57
c. Feeling guilty or upset about "bad numbers"	21.8	58.1	20.2	1.98	.65
d. Not knowing how or if to tell others about their diabetes	65.0	22.0	13.0	1.48	.72
e. Others asking about their pump/injections/monitor	65.9	22.8	11.4	1.46	.69
f. Parents bugging them to take care of themselves	35.8	48.0	16.3	1.80	.70
g. Going to clinic often and missing school	62.1	29.8	8.1	1.46	.64
h. Seeing their family worry about them	40.5	38.0	21.5	1.81	.77
i. Teachers/coaches/nurses/peers at school don't understand their diabetes	52.4	41.9	5.6	1.53	.60
j. Having diabetes get in the way of their personal goals	46.0	44.4	9.7	1.64	.65

Table 2

Parent Reports of Children's Stress: Percentages and Means (SDs)

	Never stressful	Sometimes stressful	Stressful a lot of the time	M	SD
a. Feeling different from other kids	27.7	64.5	7.7	1.80	.56
b. Dealing with diabetes care (e.g., paying attention to what they eat, checking blood glucose, taking supplies wherever they go)	11.5	54.5	34.0	2.24	.64
c. Feeling guilty or upset about "bad numbers"	25.6	51.9	22.4	1.97	.69
d. Not knowing how or if to tell others about their diabetes	60.9	35.3	3.8	1.43	.57
e. Others asking about their pump/injections/monitor	67.7	28.4	3.9	1.36	.56
f. Parents bugging them to take care of themselves	24.5	51.6	23.9	1.99	.70
g. Going to clinic often and missing school	57.1	35.9	7.1	1.50	.63
h. Seeing their family worry about them	38.5	48.1	12.8	1.73	.68
i. Teachers/coaches/nurses/peers at school don't understand their diabetes	36.8	48.4	14.8	1.78	.69
j. Having diabetes get in the way of their personal goals	51.9	39.0	9.1	1.57	.66

Table 3

Children's Reports of How Much Help They Need Coping With Stressors by Age Group: Percentages and Means (SDs)

	Never needs help	Sometimes needs help	Needs a lot of help	M	SD
10-13 years	16.28	69.77	13.95	1.67	.36
Older than 13 years	32.65	67.35	0	1.63	.34

Table 4

Parent Reports of How Much Help Children Need Coping With Stressors by Age Group: Percentages and Means (SDs)

	Never needs help	Sometimes needs help	Needs a lot of help	M	SD
Younger than 10 years	2.56	82.05	15.38	1.58	.29
10-13 years	2.38	78.57	19.04	1.82	.38
Older than 13 years	21.05	60.53	18.42	1.83	.43

Table 5

Percentage of Parents' Reports for Each Child Life Service

	Needs this service	Received this service	Satisfied with this service
Developmental Support	21.4	18.0	74.1
Health Care Play	16.9	20.0	69.7
Expressive Play	16.1	10.8	57.1
Therapeutic Dialogue	40.3	18.1	60.7
Preparation	19.5	18.6	62.1
Procedural Support	24.5	18.6	77.8
Family Facilitation	30.5	22.1	75.8

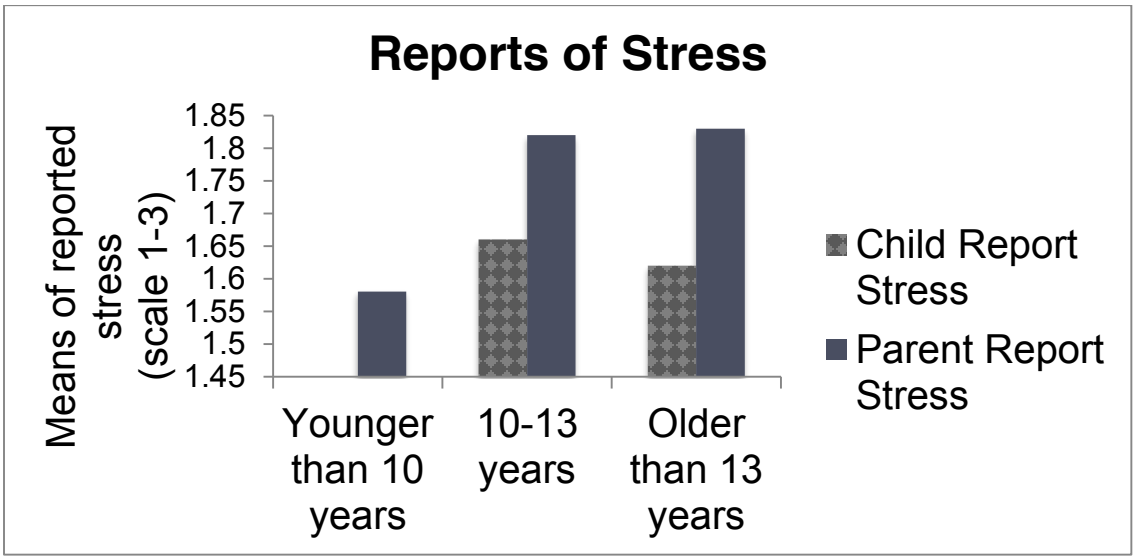

Figure 1. Reports of stress.

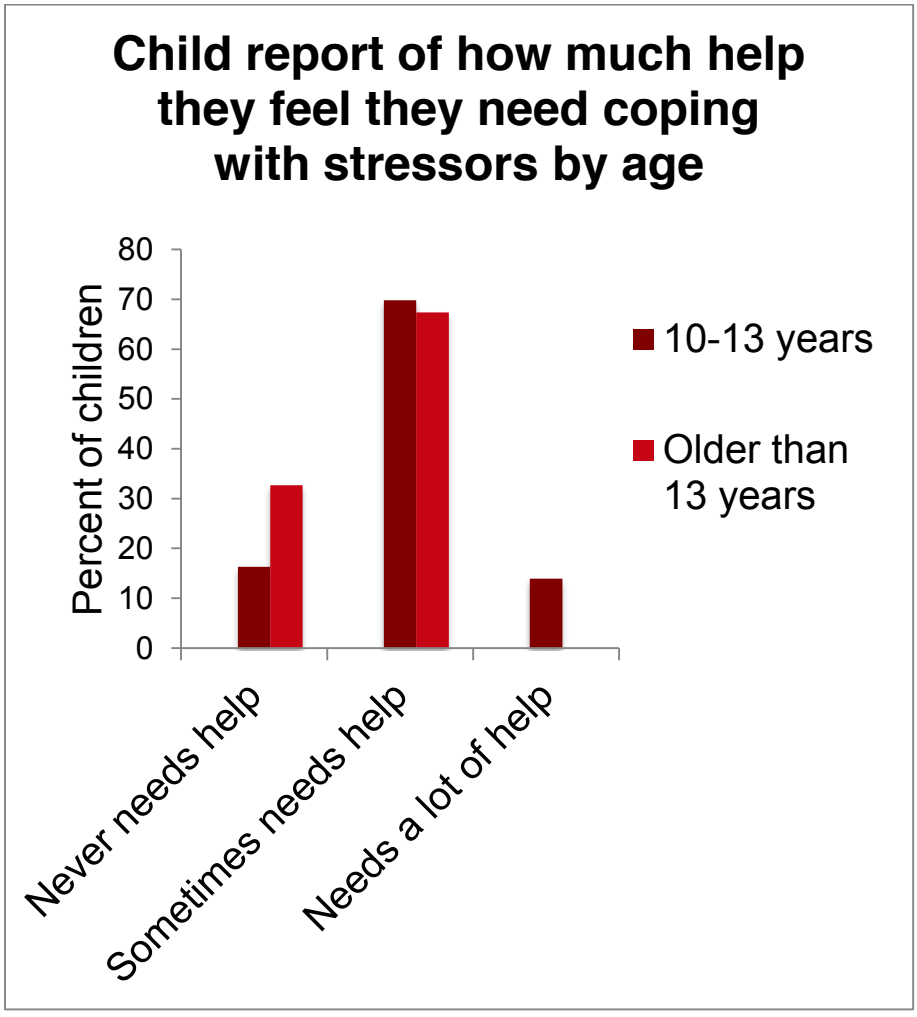

Figure 2. Child report of how much help they feel they need coping with stressors by age.

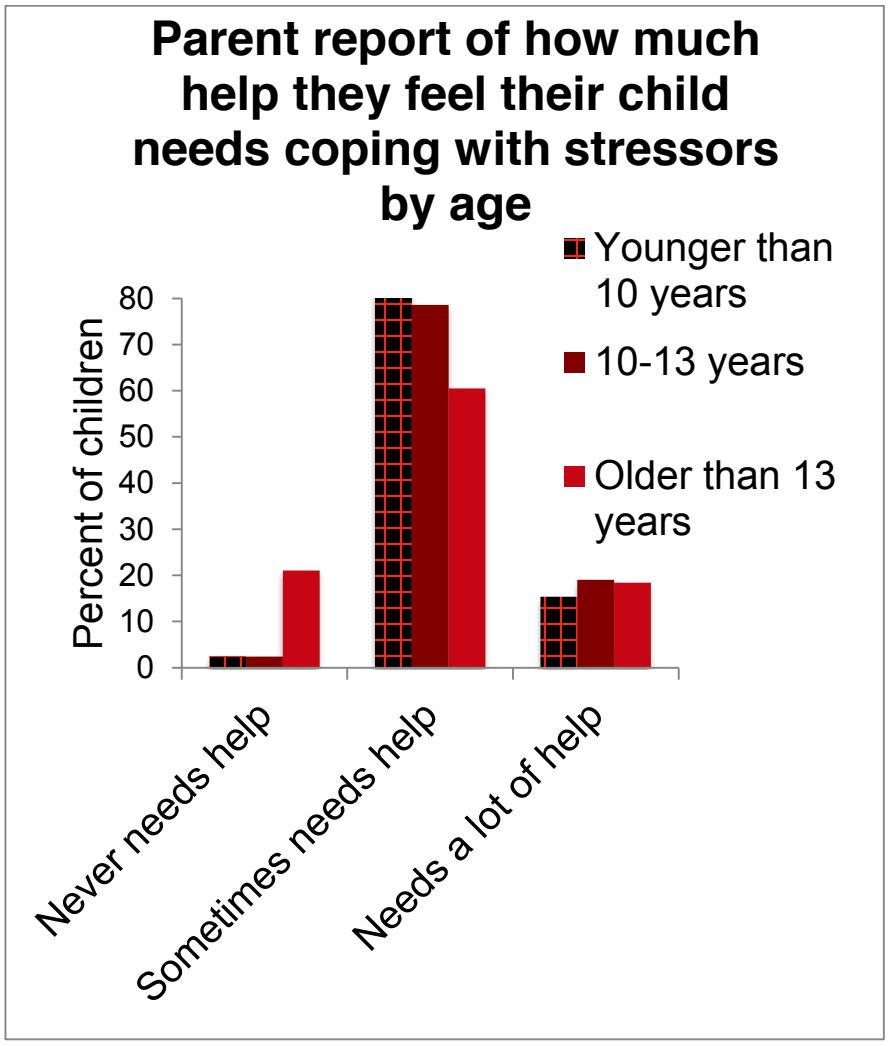

Figure 3. Parent report of how much help they feel their child needs coping with stressors by age.

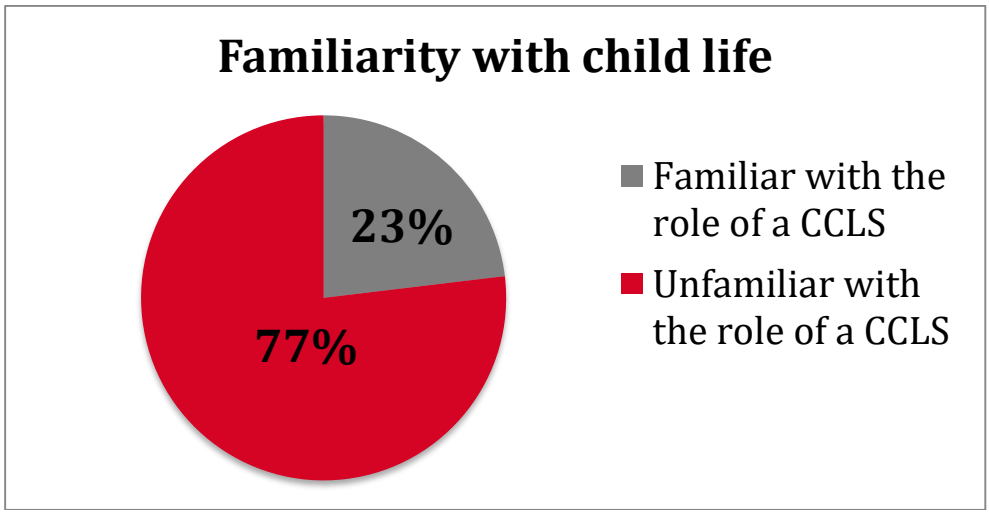

Figure 4. Familiarity with child life.

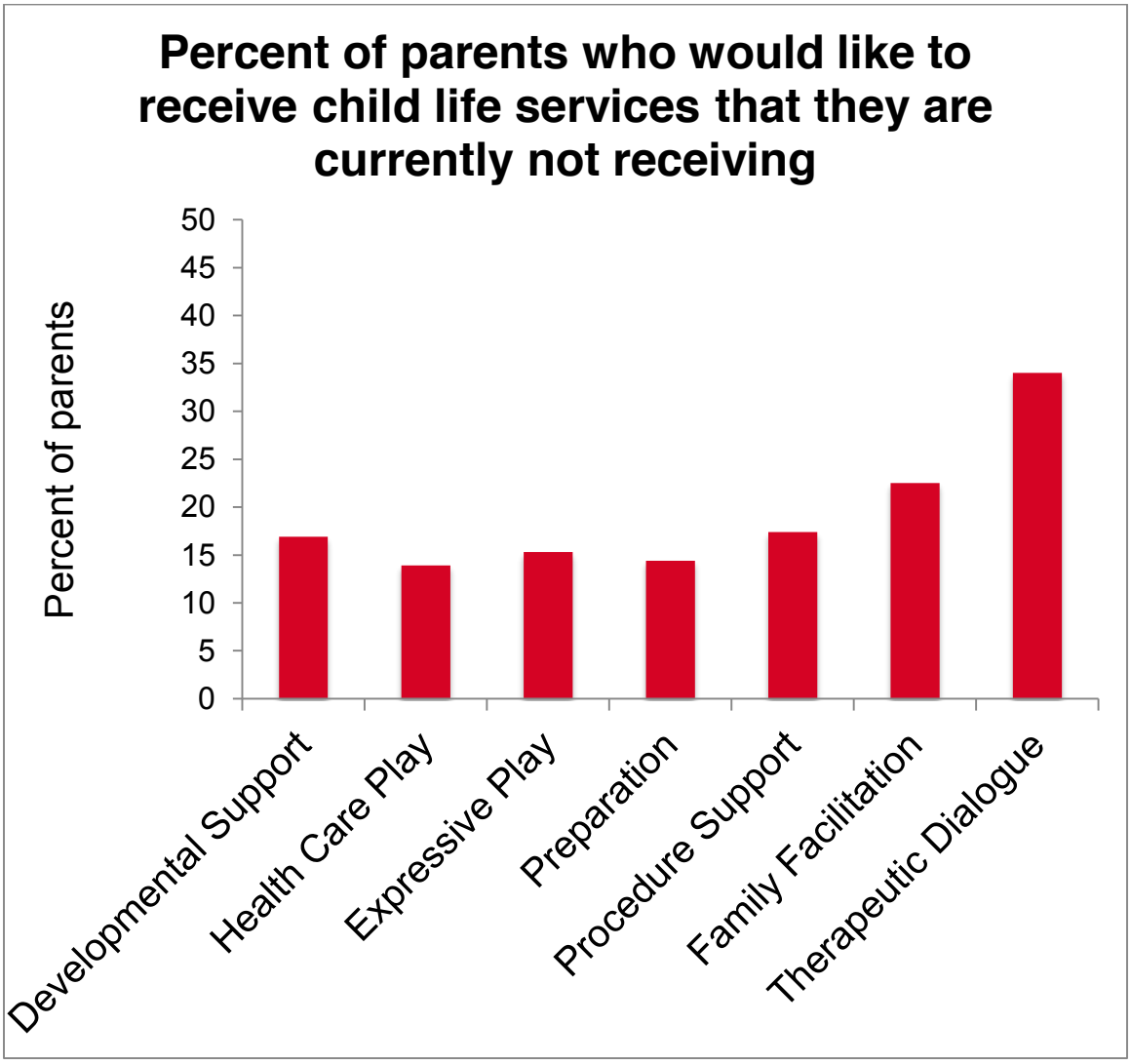

Figure 5. Percent of parents who would like to receive child life services that they are currently not receiving.

DISCUSSION

This study is the first to examine the role CCLSs can play in helping children with diabetes cope with their illness. Studies have researched how children and adolescents cope with DM, and how CCLSs use coping strategies in general, but no research has examined the role child life plays in helping patients with diabetes cope. The results of the study demonstrate that children with diabetes typically need help coping with the stress of diabetes, even though high stress levels for children were not reported. CCLSs can support children's coping strategies through developmental support, health care play, expressive play, therapeutic dialogue, preparation, procedural support, and family facilitation. Gaps existed for all of these services, in which participants desired services that were not being received. This gap provides an opportunity for CCLSs to address the need for services.

Given the results, it appears children were experiencing a moderate to low amount of stress due to their diabetes. Given the research that diabetes is very stressful for children and adolescents, this finding was surprising. The children's reports indicated that girls were more stressed than boys; this finding is consistent with other research on adults with diabetes (Siddiqui, Khan, & Carline, 2013). The parent reports did not show any differences in stress levels between boys and girls. This finding in sex differences revealed by the children's data could be due to the fact that females experience more social pressure, or that they are more willing to

admit to being stressed. It could be very beneficial for researchers to continue to study gender differences in diabetes-related stress.

For the parent reports it was indicated that older children were more stressed than younger children. A possible explanation for this could be that parents of younger children manage their diabetes for them so they don't have to think about it as much, but teens have more of a responsibility to manage their diabetes on their own. It also could have been that the items we asked about were more relevant for older children compared to younger children (e.g. "having diabetes gets in the way of personal goals"). Davidson et al. (2004) reported that the teens in their study had a hard time balancing the stressors that came from being an adolescent and the stressors that came from having diabetes. Due to the fact that being a teen in general comes with its own set of challenges, it is not surprising to find that diabetes adds to that stress. Looking at differences between children's reports and parents' reports could be another beneficial area for future researchers to look into in order to give some insight into why parents and children aren't reporting the same results.

Previous studies have suggested that youth with diabetes may need additional psychological support to deal with managing their disease and coping with the stressors associated with it (Davidson et al., 2004; Freeborn et al., 2013). The results of our study are consistent with this finding, and the majority of our participants perceived that they at least sometimes needed help coping with their diabetes.

The CCLS, who is an important member of the healthcare team, offers one

potential source of support for children with diabetes in the healthcare setting. The majority of parents surveyed were not aware of the role of CCLSs and the services they can provide. Due to this fact, more awareness of the profession needs to be promoted.

For all of the child life services listed on the survey, gaps existed with services being desired that were not being received. The biggest gaps existed for therapeutic dialogue and family facilitation. These services may have been the most desired services because the majority of our sample was older children, and perhaps younger children need the other services more. This gap provides an opportunity for CCLSs to address the need for services.

A weakness of this study is that we were only able to collect data from patients of Primary Children's Diabetes Clinic in Salt Lake City, Utah. Therefore, our results might not be completely generalizable to the rest of the population of children with diabetes.

This study not only benefits children with DM and their families, but the field of child life as well. It identifies what services children and adolescents with DM are already receiving at the Diabetes Clinic at Primary Children's Hospital, as well as what gaps currently exist and how CCLSs may potentially fill those gaps. It contributes to the small but growing body of research on the child life field. It also helps to demonstrate a need for having a full time CCLS present in the diabetes clinic at Primary Children's Hospital.

APPENDIX

Child/Adolescent Survey

Demographics:

Are you a Boy / Girl (circle one)

How old are you? _____

How hard have these things been for you in the past 6 months?

	Never Hard	Sometimes Hard	Hard a lot of the time
a. Feeling different from other kids	1	2	3
b. Dealing with diabetes care (e.g., paying attention to what you eat, checking blood glucose, taking supplies wherever you go)	1	2	3
c. Feeling guilty or upset about "bad numbers"	1	2	3
d. Not knowing how or if to tell others about your diabetes	1	2	3
e. Others asking about your pump/injections/monitor	1	2	3
f. Parents bugging you to take care of yourself	1	2	3
g. Going to clinic often and missing school	1	2	3
h. Seeing your family worry about you	1	2	3
i. Teachers/coaches/nurses/peers at school don't understand your diabetes	1	2	3
j. Having diabetes gets in the way of your personal goals (e.g., not being able to sleep at your friend's house, getting driver's license)	1	2	3

Circle the number that shows how much help you think you need dealing with these challenges now.

1 (Never need help) 2 (Sometimes need help) 3 (Need a lot of help)

When dealing with a problem related to your diabetes, how often do you…

	Never	Sometimes	A lot
Spend time with family or friends	1	2	3
Try to fix the problem by doing something	1	2	3
Cry or yell to let all of your feelings out	1	2	3
Try to distract yourself with media or other activities	1	2	3
Try to see the positive side of things	1	2	3
Pretend it never happened and try to forget about it	1	2	3
Talk about your feelings with someone	1	2	3
Pray that things will change	1	2	3
Feel bad for yourself	1	2	3
Do something bad or to cause trouble	1	2	3
Wish for a miracle	1	2	3
Take it out on yourself	1	2	3

Parent Survey about Coping with Diabetes

1. **Stressors:**

This is a list of things about diabetes that children and teenagers sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following issues have been for your child in the past 6 months.

	Never stressful	Sometimes stressful	Stressful a lot of the time
a. Feeling different from other kids	1	2	3
b. Dealing with diabetes care (e.g., paying attention to what they eat, checking blood glucose, taking supplies wherever they go)	1	2	3
c. Feeling guilty or upset about "bad numbers"	1	2	3
d. Not knowing how or if to tell others about their diabetes	1	2	3
e. Others asking about their pump/injections/monitor	1	2	3
f. Parents bugging them to take care of themselves	1	2	3
g. Going to clinic often and missing school	1	2	3
h. Seeing their family worry about them	1	2	3
i. Teachers/coaches/nurses/peers at school don't understand their diabetes	1	2	3
j. Having diabetes get in the way of their personal goals (e.g., getting driver's license)	1	2	3

2. Circle the number that shows how much help your child needs in coping with these stressors now.

1 (Never needs help) 2 (Sometimes needs help) 3 (Needs a lot of help)

3. **Coping:**

When dealing with a problem related to their diabetes, how often does your child…

	Never	Sometimes	A lot
Spend time with family or friends	1	2	3
Try to fix the problem by doing something	1	2	3
Cry or yell to let all of their feelings out	1	2	3
Try to distract themselves with media or other activities	1	2	3
Try to see the positive side of things	1	2	3
Pretend it never happened and try to forget about it	1	2	3
Talk about their feelings with someone	1	2	3
Pray that things will change	1	2	3
Feel bad for him/herself	1	2	3
Do something bad or to cause trouble	1	2	3
Wish for a miracle	1	2	3
Take it out on themselves	1	2	3

Perceptions of role of child life:

We would like to learn what parents feel about the role of child life specialists at Primary Children's Hospital. Child life specialists are trained professionals whose job is to help children cope with being in the hospital and with other stressful events.

4. Did you know about the role of a child life specialist before arriving at the PCH clinic?

- ☐ Yes
- ☐ No

5. Below are a series of things that child life specialists might do when working with children and their families. Please read each definition and circle the responses that best apply.

	Does your child need this service?	Has your child received this service?	If so, how satisfied are you with this service?
Developmental Support Definition: One-on-one interaction to help maintain and/or encourage progress in developmental skills (e.g. autonomy)	Yes / No	Yes / No	Very Somewhat Not at all
Health Care Play Definition: Play session that helps your child express feelings/ worries/questions about hospitalization; develop coping strategies; clear up misunderstandings and work though feelings about painful or scary experiences. This might include using body outline dolls and medical supplies.	Yes / No	Yes / No	Very Somewhat Not at all
Expressive Play Definition: Play session that helps your child express feelings/ worries/questions about hospitalization work though feelings. This may include the use of toys, art or role playing etc.	Yes / No	Yes / No	Very Somewhat Not at all
Therapeutic Dialogue Definition: Talking with your child to explore concerns, coping strategies, clear up misunderstandings and work though feelings about painful or scary experiences.	Yes / No	Yes / No	Very Somewhat Not at all
Preparation Definition: Using conversation, photographs and/or play to explain medical procedures or surgery in a way that makes sense to your child, that allows questions to be asked and coping strategies to be learned.	Yes / No	Yes / No	Very Somewhat Not at all

Procedural Support Definition: The child life specialist provides support when a procedure/medical test is taking place and uses strategies to help your child to cope better.	Yes / No	Yes / No	Very Somewhat Not at all
Family Facilitation Definition: Provides information to help your family understand the hospital system; listens to concerns and provides emotional support; may provide parenting guidance; support for brothers and sisters and encourages parent-child interactions.	Yes / No	Yes / No	Very Somewhat Not at all

6. Are there child life services you would like access to? If so, which ones?

7. Now that you know about coping with the stress of diabetes, is there anything you wish you had known previously?

8. What advice would you give other parents about coping with the stress of pediatric diabetes?

Background Information

9. What is your child's gender? Female _____ Male _____

10. Child's Age _____ 11. Child's Birthdate _____

12. How old was your child when diagnosed? _____

13. Which race/ethnicity best describes your child? (check one)
- ___ American Indian or Alaskan Native
- ___ Asian/Pacific Islander
- ___ Black or African American
- ___ Hispanic/Latino
- ___ White/Caucasian
- ___ Multiple Ethnicities (please specify _____)

14. What is your relationship to your child? (check one)
- ___ Mother
- ___ Father
- ___ Grandparent
- ___ Guardian
- ___ Other (Please specify _____)

15. What is your highest level of education completed? (check one)
    ___ Some high school
    ___ High School Diploma
    ___ Some College
    ___ College Degree or More

16. What type of diabetes does your child have? (circle one)
    Type 1 Type 2 Other
    _____

17. How many times has your child been to the Emergency Room for problems related to their diabetes? _____

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