



2012-07-09

Evaluating the Effectiveness of a Workshop/ Support Group for Parents Raising Children with Type 1 Diabetes

Christina Marie Yazzie

Brigham Young University - Provo

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Evaluating the Effectiveness of a Workshop/Support Group
for Parents Raising a Child with Type 1 Diabetes

Christina Yazzie

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

Donna Freeborn, Chair
Barbra Mandelco
Susanne Olsen Roper

College of Nursing
Brigham Young University

August 2012

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ABSTRACT

Evaluating the Effectiveness of a Workshop/Support Group

for Parents Raising a Child with Type 1 Diabetes

Christina Yazzie
College of Nursing, BYU
Master of Science

The purpose of this study was to evaluate the effectiveness of a workshop/support group for parents raising children with type 1 diabetes mellitus (T1DM). Diagnosis of a chronic disease in a child generally arouses acute anxiety and stress in parents. Parental stress when raising a child with type 1 diabetes is often centered on worry about their child's health and parents' ability to maintain the care activities needed by these children. Parents are the primary caregivers of children with Type 1 diabetes, and the effect of stress on parents can impact the health of both children and parents. The present study examined parents of children with type 1 diabetes who attended four separate two hour support groups/workshops. The Pediatric Inventory for Parents (Streisand, 2001) measured parenting stress. The parents completed the Pediatric Inventory for Parents, at the beginning of the first workshop and again at the end of all the workshops. Parents also completed an open ended questionnaire at the end of each workshop. Parents responded positively to the workshops. Parents stated that hearing how others worked through difficult situations while raising their child with type 1 diabetes was helpful. In quantitative analyses, parents had lower mean scores, post- vs. pre- test on measures of stress related to emotional functioning, communication, medical care, and role function. Research shows that support groups that involve the entire family are most beneficial (McBroom & Enriquez, 2009). Nurse practitioners should consider sponsoring or becoming involved in workshops for parents raising children with type 1 diabetes.

Keywords: diabetes, type 1 diabetes mellitus, parents, chronic illness, support group

ACKNOWLEDGEMENTS

I would like to express my appreciation to the faculty and staff at Brigham Young University for the excellent education and experience I have received throughout graduate school. A special thanks to Dr. Donna Freeborn for all of her guidance, patience and understanding while working on this thesis. She provided the vision, encouragement, support and advice needed for me to finish this project. I would also like to thank Barbara Mandleco for her invaluable editing and insightfulness, as well as Susanne Roper for taking the time to help me organize the statistics in this paper. I have to thank my parents for instilling in me a love of education and the self-confidence for me to reach for my dreams. Lastly I must send a heartfelt thank you to my husband Bryan and our four wonderful boys for being by my side every step of this journey. Without your amazing support I could never have fulfilled so many of my dreams in life.

TABLE OF CONTENTS

TITLE PAGE.....	i
ABSTRACT	ii
ACKNOWLEDGEMENTS.....	iii
Evaluating the Effectiveness of a Workshop for Parents Raising Children with Type 1 Diabetes.....	1
Methods	4
Sample	4
Procedure	4
Measures.....	5
Parenting stress.....	5
Evaluation of workshop.....	5
Data Analysis.....	6
Results	6
Quantitative Analyses.....	6
Qualitative Analyses.....	7
Workshop #1.....	8
Workshop #2.....	9
Workshop #3.....	11
Workshop #4.....	14
Discussion of Findings	16
Limitations.....	21
Implication for Clinical Practice.....	22
References	24
Appendix A.....	29
Appendix B.....	30
Appendix C.....	32
Appendix D	33

Evaluating the Effectiveness of a Workshop for Parents Raising Children with Type 1 Diabetes

Parenting a child with a chronic illness can result in significant physical and psychological strain (Streisand, Mackey, & Herge, 2010). Diagnosis of a chronic disease in a child such as type 1 diabetes mellitus (T1DM) generally arouses acute anxiety and stress in parents; strong emotions such as fear, anxiety, grief, and guilt are also common (Tsampanli-Kitsara & Kounenou, 2004). Parents raising a child with a chronic illness are: (a) burdened with monitoring the child's physical symptoms; (b) responsible for providing complicated medical care or establishing a complex treatment regimen; (c) worried about the child's development and long term health, and (d) overwhelmed with their own complex emotions related to the child's illness (Anderson, Loughlin, Goldberg, & Laffel, 2001).

Type 1 diabetes mellitus is a common severe chronic illness in children. The number of people diagnosed with diabetes in the United States has grown from 5.6 million in 1980 to approximately 18.1 million in 2008; 215,000 people under the age of 20 have diabetes, with 15,000 diagnosed yearly with T1DM (Center for Disease Control and Prevention, 2011; "National Diabetes Fact Sheet, 2011", 2011). The incidence of T1DM also is increasing worldwide (Berhan et al., 2011, Harjutsalo, Sjoberg, & Tuomilehto, 2008, Patterson et al., 2009,).

T1DM is a disease of insulin deficiency occurring after pancreatic beta cells have been damaged and usually occurs during childhood. Insulin is a hormone needed to absorb and utilize glucose; however, when the pancreas is damaged and unable to produce insulin, circulating levels of glucose in the blood increase. Although childhood T1DM onset presents in many ways, the classical symptoms result from hyperglycemia and include increased thirst, frequent urination, weight loss in spite of an increased appetite, and lethargy (Levitsky & Misra, 2011).

Management can be time consuming and stressful for both children with T1DM and their parents. Management includes blood glucose monitoring day and night, insulin injections or use of an insulin pump, dietary planning, regular exercise, and the ability to identify and manage periods of hypo- and hyperglycemia (Monaghan, Hilliard, Cogen, & Streisand, 2009, Streisand, Mackey, & Herge, 2010, Sullivan-Bolyai et. al., 2010). In fact, nearly every childhood activity including eating, sleeping, attending school and playing has some effect on blood glucose levels and control, making blood glucose control particularly difficult in children (Coffman, 2001).

Children's age and developmental levels make management of T1DM particularly challenging. First, the child's ever changing size and weight makes insulin dosing difficult. Second, a child's dietary intake and activity level can also be unpredictable, thereby increasing the risk for developing hypoglycemia. Finally, it is often difficult to distinguish normal developmental behaviors from behaviors caused by high or low blood glucose. (Levitsky & Misra, 2011)

The diagnosis of T1DM in a child triggers strong emotional responses from parents; they are often overwhelmed and report anxiety, stress, and feelings of isolation, worry and even grief (Bowes, Lowes, Warner, & Gregory, 2009, Streisand et al., 2010, Sullivan-Bolyai et al., 2010). Specifically, parental stress is commonly centered on worry for the child's health and parents' ability to manage their child's diabetes (Streisand et al., 2010, Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Since parents are usually primary caregivers; parental stress can affect the health of both the child and parents (Anderson, Loughlin, Goldberg, & Laffel, 2001). For example, higher parent stress levels are associated with poorer overall health and a variety of physical and psychological symptoms in their children with T1DM (Streisand et al., 2010). In addition, a Taiwanese study discovered caregivers of people with diabetes score significantly

lower on quality of life measurements and have more health problems compared to the general population (Li, Lee, Lin, & Amidon, 2004).

Support groups for parents of children with chronic illnesses are becoming popular. For example, families with adolescents with T1DM report a short term support intervention helps improve parent coping skills (Konradsdottir & Svavarsdottir, 2011). In addition, Sullivan-Bolyai and colleagues (2004) evaluated a parent mentor support intervention in which parent mentors (parents who had managed T1DM for a long time) were available through phone calls or face-to-face meetings for parents with a recently diagnosed child with T1DM. These investigations discovered less parental concern and greater confidence in dealing with a chronically ill child. However, when Sullivan-Bolyai and colleagues (2009) compared a parent mentoring program to a control group they found no difference in levels of worry and concern or in the amount of perceived support received. However, a group intervention for adolescents with T1DM in Norway that included peer group support and meetings, positively affected hemoglobin A1C levels (Loding, Wold, & Skavhaug, 2008).

Indeed, parent support groups are helpful for parents raising children with T1DM; however, there is little information in the literature regarding specifics of these support groups. Therefore, the purpose of this project was to evaluate the effectiveness of a workshop/support group for parents raising children with T1DM in decreasing stress and increasing comfort in caring for their child and to gather information during the workshops about parental perceptions of the usefulness of the groups.

Methods

Sample

After obtaining university and hospital Institutional Review Board approval, parents raising a child with T1DM were recruited to participate in workshops through fliers placed at diabetes clinics, referrals from health care providers, diabetes summer camps, and snowball sampling. Ten parents from seven different Caucasian families agreed to participate. All participants were raising a child with T1DM and had at least a high school education. Only one parent reported highest level of education as high school; the remainder had attended college, and two attended graduate school. Parent ages ranged from 30 to 51 with a mean of 38. The families were two parent families, raising a biological child with T1DM and between 2 and 5 other children. All fathers were employed full time; two mothers were employed part time. Reported annual incomes ranged from 50,000 to over 100,000 dollars.

Procedure

Parents were invited to attend four two-hour workshops held once a month for four months. The workshops discussed challenges of raising a child with T1DM previously identified. The first workshop addressed issues related to school, the health care system, and the community. The second workshop focused on parenting issues and parental problems with physical management of the disease. The third workshop addressed siblings, extended family and friends. The fourth workshop centered on physical management of diabetes as well as the future of diabetes and diabetes research.

Each parent attending the workshop completed the Pediatric Inventory for Parents (PIP) (Streisand et al., 2001), which measures stress in parents raising a chronically ill child, at the first and last workshop. Each parent was asked to fill out an individual PIP pre- and post-

intervention; however, two couples filled out individual PIP pre-workshop, but filled out a joint PIP post-workshop. At the end of each workshop parents also individually completed an open-ended questionnaire. Notes were taken during each workshop outlining the discussion, parent suggestions, and information learned during the workshop.

Measures

Parenting stress. The PIP (Streisand et al., 2001) measures parenting stress specifically related to caring for a child with a chronic illness. It is a 42-item self-report rating which evaluates four domains of potential stressors: emotional functioning, communication, medical care, and role function. Parents rated how often an event had occurred in the previous 7 days and how difficult it was in general. Events such as: difficulty sleeping, speaking with doctor, feeling confused about medical information, or knowing my child is hurting or in pain; were rated for frequency of occurrence as well as difficulty coping with the event. Parents responded to each item by using a Likert scale ranging from 1 = “Never” to 5 = “Very often” for frequency of stressor and 1 = “Not at all” to 5 = “Extremely” for difficulty of stressor. Higher scores indicate greater parenting stress related to more frequent and more difficult stressors (Streisand et al., 2001). Previous research has shown that the measure has good reliability and validity (Streisand et al., 2001, 2005, 2010; Lewin et al., 2005).

Evaluation of workshop. Parents also responded to an open ended questionnaire at the end of each workshop. Questions included: What did you find helpful about today’s workshop? How has attending this workshop impacted your stress level? What are some of the challenges of raising a child with diabetes? How has raising a child with diabetes impacted your life?

Data Analysis

The PIP was analyzed by calculating mean scores pre- and post- intervention for each domain. Due to the small sample size no other statistics were calculated. Notes taken during the workshops and written answers to open ended questionnaires were analyzed using qualitative analysis. Questionnaires were tagged with an ID number, recurrent themes were identified, and specific concerns and answers to questions were looked at to identify frequent areas of parental concern, parental perceptions about workshop usefulness and effectiveness and the impact of the workshops on parental stress.

Results

The purpose of this project was to evaluate the effectiveness of a workshop/support group provided to parents of children with T1DM to help decrease their stress and increase their comfort in caring for their child.

Quantitative Analyses

Tables 1 and 2 show the pre- vs. post-intervention means for the four domains assessed using the PIP. The main category of frequency of stressor and difficulty of stressor are further assessed in relation to communication, emotional disturbance, medical care, and role functioning.

Table 1 shows the frequency with which parents were faced with challenges related to their child with diabetes. Overall mean frequency of scores decreased from the beginning of the workshops to the end, with a decrease in mean within each domain as well. There was a 1 point drop in mean in the domains of emotional, communication, and medical care, while there was a 3 point drop in the domain of role function. Over all there was a drop of 5 points in the mean of frequency of challenges encountered.

Table 2 shows parental ratings of how difficult it was to deal with the challenges they faced raising a child with T1DM. Overall mean difficulty rating dropped; there was also a drop in the mean difficulty ratings within each domain. Emotional difficulty mean dropped by 0.5 of a point, role function mean difficulty dropped by 2 points, communication difficulty mean dropped by 3 points, and medical care difficulty mean dropped by 4 points pre- vs. post-intervention. Overall there was nearly a 10 point decrease in the perceived difficulty scores. Although mean frequency of challenges decreased pre- vs. post-intervention, there was twice the drop in perceived difficulty of challenges pre- vs. post-intervention.

It is interesting to note that while the overall scores decreased there were some individual increases in scores pre- vs. post intervention. Husband and Wife #1 has increased frequency scores on both communication and medical care. Husband #1 also had an increased frequency score in role function and a total frequency score increase. However, on difficulty ratings only Wife #1 not Husband #1 showed any increased scores pre vs. post intervention. Wife #3 showed an increase in both emotional frequency and difficulty. Husband #5 scored a minor increase in frequency scores related to role function, yet showed increased difficulty scores in all domains. Wife #6 scored slightly higher in communication frequency but had no increased difficulty scores.

Qualitative Analyses

Each workshop focused on parent-identified challenges of raising a child with T1DM. Information and topics were introduced for the month; there was an exchange of ideas and discussion between parents and presenters. Parents completed an open-ended questionnaire at the end of each workshop about their experience that day. Although each workshop had planned topics, the conversation was left open to parent interests and discussions.

Workshop #1. The first workshop addressed issues related to school, the health care system, and the community. A power point presentation about state laws, rights of families, 504 medical treatment plans, and the school system was presented.

Discussion. School created many stresses for the families. Parents did not want their child to feel different; however, diabetes management activities often singled them out. Parents reported public school teachers wouldn't let the children with T1DM eat treats brought to class because they were unsure how to deal with the diabetes. Parents also reported they had been required by local elementary schools to accompany their child on field trips, which also made the children feel singled out and different. Parents identified school personnel's lack of knowledge about T1DM as stressful.

During discussion it was discovered that all the parents who attended the workshop transferred their children out of local elementary schools where minimal help was provided for diabetes management to charter schools (state funded private schools) where a full time nurse was available and each child was assigned a diabetic aide during school hours. The charter schools also developed a 504 medical management plan with parents and allowed children with T1DM to participate in extra-curricular activities, which had been denied at the local elementary schools.

Written questionnaire. When asked in the written questionnaire, what did you find helpful about today's workshop, parents reported that the discussion about school challenges was helpful. Parental responses included, "[I] found new things to add to 504 plans (medical directive plans) [and] about new advocacy helps;" "Learning that there are lots of advocates and people out there to help (with school problems)." In describing how attending the workshop had

impacted their stress levels, parents responded, “Glad to know that we’re not the only ones that struggle.”

Workshop #2. The second workshop focused on emotional challenges of raising a child with T1DM. Topics discussed included: coping with child’s initial diagnosis, controlling tantrums, dealing with sick days, feeling different, and management during the teen years. Information on being prepared for sick days and preparing for managing the challenges associated with teenage diabetes control was presented, although the majority of the time was spent in parents sharing their own ideas and what has worked for their families.

Discussion. Parents discussed their emotions at the time of diagnosis including fear, denial and even guilt (because of the genetic component of the disease). Fear was identified as a significant stressor and included fear for the sick child and fear other children might be diagnosed as well. One father admitted even though it’s been years since the diagnosis he still struggles with denial, and wants to think one day there will be a cure.

Discipline was another challenge, and included temper tantrums and entitlement. T1DM was identified as the source of tantrums for one preteen: “When the levels (blood glucose levels) dip or spike, they lose control and are crazy.” T1DM was also used as an excuse by children who wanted special treatment. Parents shared strategies to reduce these entitlement issues such as letting children know they are loved, but their behavior is not acceptable, and not allowing children with T1DM to have “special” rules or conditions different from their siblings.

While none of their children were teenagers, parents of 10 and 12 year olds, were nervous about the approaching years. In fact, two families were already seeing challenges typical of teenage diabetes control: (a) noncompliance, (b) having to remind the children to check blood sugars and getting upset, (c) how to tell children “we trust you- we just don’t trust your age”, and

(d) self-consciousness about their body. These parents also described how difficult it was relinquishing control: “I always worry about how she’s doing or if she’s going to have a seizure.” One family who struggled with a noncompliant child was even threatened by a doctor with a call to Child Protective Services if their daughter’s blood glucose levels weren’t controlled. Parents felt people didn’t understand how difficult it was to manage their children’s diabetes, particularly when the children neared adolescents.

Another emotional challenge was helping the child with T1DM to not feel different from other children their age. For example, one set of parents struggled with their daughter’s high blood glucose at dinner, which often led to her not eating with the family, or she received a modified dinner. Other parents were startled by this and explained they didn’t wait to eat dinner with the family because they don’t want him/her to feel different. If their child had high blood glucose, they administered more insulin and let the child eat the same dinner as the family. Parents were also concerned about their children not feeling different at school so. When treats would be available at school, one parent went to school to monitor the child’s blood glucose and administer insulin appropriately so the child could enjoy treats with the other children.

Written questionnaire. When asked in the written questionnaire, what did you find helpful about today’s workshop, parents stated “Talking about how to deal with children’s behavior and getting ideas about how to care for our children” “Talking with other parents with similar concerns.” “I love to hear the perspectives and experiences of other parents.” “It was very helpful for discussions and peer therapy.” In describing how attending the workshop had impacted their stress levels, parents responded, “We’re pretty laid back already, so we don’t really feel stress about diabetes.” “It’s nice to hear others have similar concerns – that is helpful.” “It has helped me think about how to deal with stressful situations.” Since this month

focused on challenges, parents listed several of the challenges of raising a child with diabetes? “Parenting when your child is out of control.” “Helping them to not feel different than other children their age.” “Helping them learn to “own” it (diabetes).” “Getting her to take care of herself.”

Workshop #3. The third workshop focused on siblings and extended family members. Parents discussed both positive and negative situations related to families. One grandmother attended with her daughter whose 5-year-old son had T1DM and provided insight from a different perspective.

Discussion. One family included the siblings in diabetes management since their son’s diagnosis. Most families taught siblings about diabetes, signs of hypo- and hyperglycemia, and how to get help in a crisis. One parent related an incident when their son went into diabetic shock from critically low blood glucose: “Our kids got really upset; they thought they were going to lose their brother.” Now they all have learned to recognize the signs of low blood sugar.

Although children are concerned about the effects of T1DM on their sibling, negative issues arise. Feelings of jealousy between siblings arise and parents are confronted with enforcing separate rules because of diabetes. Snacks were a particular concern: “Our other kids will say it’s not fair that he gets to have a snack” when his blood glucose level was low. Another problem was too many snacks. To address this problem, one family found that instead of singling out their child with T1DM by not letting her go trick or treating, the whole family goes trick or treating and can eat candy that night, but the next day the parents buy all the candy. The kids love getting money for their candy and everyone is treated the same with no extra candy or snacks around the house.

Interactions with extended family have been frustrating for some and helpful for others. Some grandparents are willing to learn and help but others are afraid to babysit. One mother stated,

I went to Girl's Camp three weeks after my son's diagnosis, so we were forced to depend on our in-laws for help. I don't think the transition would've happened if I hadn't gone to girls' camp. It enabled other extended family member to become involved.

On the other hand, all four grandparents of one boy were afraid to be around and take care of him because he also has asthma, and food allergies. They related the following negative experience: "We brought him to my husband's family and they fed him a whole pack of bacon and cheese (because they knew they were sugar free); he spent the next day in the emergency room throwing up all day." A common experience shared by all the families was grandparents' lack of knowledge about appropriate diet. Most believed people with diabetes could not eat any carbs, these grandparents seemed unwilling to change this misconception even when told it was appropriate to eat carbs in a balanced diet.

The grandmother attending the workshop with her daughter was actively trying to help with raising her grandson. She had read a lot of information and was willing to be involved, but still found it difficult. "When I first had to babysit my grandson and check his blood sugar, we both cried because it was a hard experience. I have to overcome fears to support my daughter in caring for her son." "After attending this workshop I feel much more comfortable in helping to care for my grandson."

Managing diabetes during the Thanksgiving and Christmas holidays was a concern that was brought up in relation to extended family traditions. One Jewish family talked about the

importance of food at these holidays. They were concerned their extended family had to change too many traditions to accommodate their daughter with diabetes. They felt it could be stifling and over the top to have traditions changed just to accommodate their child. Most asked their extended family not to change anything just for their children; they would rather they feel a part of the normal traditions.

Written questionnaire. When filling out the written questionnaire parents expressed something's they found helpful about the workshop: "Knowing that other parents have the same issues that I do, better understanding of the social dynamics that exist." "The facts and ideas that surfaced from the other parents." When stating how the workshop had affected stress parents stated: "It has lowered it! Talking about diabetes and its effects is stressful, but knowing we're okay and learning what to do from you and other parents is relieving. Also that you are curious not judgmental is so refreshing and comforting." "It's been therapeutic to share and hear from others with similar experiences." "Help to manage it (stress) as I find I'm not alone with my cares and concerns." Parents reported challenges of raising a child with T1DM: "Finances and work responsibilities, lack of sleep, worry and stress." "Keeping our daughter healthy." "Maintaining a physically and mentally healthy child." "Always being worried about keeping him healthy and alive. Wanting to have him a "normal" life experience." "Communicating all this knowledge with all the people he will come in contact with, helping him understand how to handle diabetes on his own." When discussing how raising a child with diabetes has impacted their lives parents stated: "Made us more aware of other's needs, also how we can help others with diabetes." "some depression – lack of sleep- lots of worry" "We're much more protective of our children." "It has made me stronger. I appreciate every moment with my precious children."

Workshop #4. The final workshop focused on advances in technology and the future of T1DM. Parents were interested in and knowledgeable about new technologies such as inhaled insulin, pills, glucose monitors that send a text message, even the new apple ipod app developed by Minimed that remotely checks insulin and controls dispensing insulin from an ipod, iphone, or ipad.

Discussion. Although parents were glad to hear about technological advances for diabetes management, they voiced their frustrations about the growing expense and felt new technologies were only a “band-aid” for diabetes. Particular interest was expressed by parents in possible cures. The father who still struggled with denial about his daughter’s disease was very well informed about possible cures for diabetes from prevention through vaccines that are being tested, to Islet cell transplantation, and even the possibility of reverse engineering stem cells. He admitted a large part of his frustration and stress comes from believing there is a cure that isn’t provided because of financial pressure from medical companies. Cost of care was a big concern, yet seemed to be offset by potential benefits of successfully treating T1DM. There was agreement that an expensive cure would be worth the expense over a less expensive management “band-aid”.

Written questionnaire. Parents reported in the written questionnaire about what they found helpful “Very informative on cures and treatments.” “All the new breakthroughs that are happening.” “Hearing about current research.” One family described how the workshops had helped their entire family (while parents attended their workshop, siblings attended a workshop just for them, and children with T1DM attended their workshop):

If you start up again our family would definitely be interested. Our children seem to care more about counting carbs and how to give shots and learning

how to give a glucagon shot. Previously that was all on Mom and Dad and our diabetic daughter.

This same family was certain that the family workshops were responsible for getting their daughter's A1c level down the lowest it had ever been.

Many recurring themes resurfaced from month to month, especially when parents reported on the challenges of raising a child with T1DM. "Letting others help is hard." This difficulty relinquishing control was often repeated. "It's hard to let others help with her diabetes. We worry about the lack of education of other people." Another recurring theme centered around the parents inability to leave their child either alone or with other caregivers. "Being able to take time away from direct health care for your child [is a challenge]. We're not able to take overnight trips away from our diabetic child." "Getting her to take care of herself [is a challenge]." "It takes lots of time and knowledge to manage diabetes. The incorrect attitude of others, and feeling good about leaving them alone [are challenges]." "We travel less, we go out more prepared, our children and treated as more fragile. We travel as a pack; we have few play dates with others. We have a hard time finding babysitters because of their fears."

Cost of care also appeared as a recurring topic of discussion and was expressed when filling out the written questionnaires. "Always wondering about blood sugars, worrying about illness, financially spending more time/money on diabetic child." "It seems to impact every aspect of our lives, it's time consuming, it's expensive and it's scary." Yet parents also felt they had learned through their challenges; "I'm more compassionate for other people's situations, (I've) become more organized and more knowledgeable about diabetes." "We no longer take eating for granted – it always requires thought. We've become more compassionate about health challenges." "It's been encouraging to see how strong our family is."

Discussion of Findings

The purpose of this research project was to evaluate the effectiveness of a workshop/support group for parents raising a child with T1DM in decreasing stress and increasing comfort in caring for their child and to gather information during the workshops about parental perceptions of the usefulness of the groups. Topics addressed in the workshops included: difficulties working with the school system, dealing with health care professionals, emotional challenges of parents, involving extended family, behavior issues of their children, diabetes control as adolescents, child care issues, work and cost of treatment as well as future treatment options and advances. Parents scored slightly lower on measures of parenting stress after completing the workshop.

Table 1 and 2 outline pre- vs. post- intervention mean scores of the parents who participated in our workshops, on the Pediatric Inventory for Parents – a measure designed to measure stress in parents raising a child with a chronic illness. Overall scores decreased in both the frequency and difficulty of stressors. The mean overall scores decreased pre- vs. post-intervention despite the fact that some individuals had increased scores within different domains. Of particular interest were the scores of Husband #5. Husband #5 scored a minor increase in frequency score (2 points) related to role function, yet showed increased difficulty scores in all domains. The ‘frequency’ mean scores dropped by 5 points even though several individuals reported higher scores in several domains. The ‘difficulty’ mean scores dropped by 10 points. There was twice the drop in perceived difficulty of challenges pre- vs. post intervention.

Diabetes is truly a family affair. This sought to discover if a monthly support group could impact and address those needs. Previous research shows support groups enable parents to

discuss issues in a relaxed atmosphere with other parents and are beneficial (Creedy et al., 2005; Coffman, 2001; Loding et al., 2008; Sullivan-Bolyai et al., 2004).

Past research examining parental perceptions regarding parenting children with diabetes found that concerns about school personnel, staff competence, and entrusting care of their child to others was a significant stressor of parents. Further, their experiences with school varied depending on the school's willingness to learn about and accommodate the child's needs (Smaldone & Ritholz, 2011). School stressors were of particular concern to the group of parents who participated in this study. They all went so far as to remove their children from the local public school and place them in a charter school because of lack of diabetes knowledge of school personnel and their treatment of their child with T1DM .

Research suggests schools have difficulty caring for children with T1DM (Jacquez et al., 2008). School personnel are often unfamiliar with the needs of children with T1DM and inadvertently prevent them from properly performing necessary self-care activities during school. Over 90% of parents are concerned about their children's diabetes care while at school and most are not aware of the federal laws applying to children with diabetes while they attend school (Jacquez et al., 2008). We found similar concerns among our parents; they felt much more comfortable in a school where there was an aide hired by the school specifically for the children with diabetes. They could sit down together at the beginning of each year and develop treatment plans and discuss various situations that might arise at school.

Interactions with healthcare professionals also repeatedly came up in discussions. Improving conversations between parents and health care providers is important (Konradsdottir & Svavarsdottir, 2011; Smaldone & Ritholz, 2011;). Of particular concern was the statement by one mother in our study of her doctor threatening to report her to child protective services if her

daughter's blood glucose was not properly controlled. Konradsdottir (2011) found healthcare providers tended to emphasize blood glucose control rather than understanding and assisting families in their everyday lives and struggles of raising a child with T1DM. Control of blood glucose levels for a child with T1DM is also a family affair. Family-centered interventions significantly improve HbA1c levels and decrease family conflict (McBroom & Enriquez, 2009). Consequently one set of parents in our group said since attending the workshop their daughters' HbA1c level was the lowest it had ever been.

It was interesting to note that the two families who reported struggling to keep their child's A1c levels normal also struggled with denial and a believed that a definitive cure for diabetes was just around the corner. Research of adolescent perspectives of living with type 1 diabetes found adolescents who believed there would be a cure in their lifetime had higher A1c levels than those who did not think there would ever be a cure (Scholes, 2009).

Parents noted that finding support in their struggles can be difficult and felt as if no one else understood the difficulty of diabetes care. Often extended family is even hesitant to baby-sit because of fear of diabetes management (Smaldone & Ritholz, 2011). This finding was reinforced many times in our study. Parents had difficulty finding qualified and willing babysitters. Extended family was often fearful of watching a child who had diabetes, and the parents listed ability to have any alone time repeatedly as a challenge of raising a child with diabetes.

Many parents found disciplining their child with T1DM particularly challenging, stating that when their blood glucose levels spike or dip they lose control and act out. They know the need to set family rules but struggle to enforce them knowing there is a biological reason for the behaviors. Hilliard et al. (2010) found that behavior problems in children have a relationship to

parental stress; parents raising children with T1DM often rated their child's behavior as more problematic than parents of healthy children. These investigations speculate, this could be due to hyper or hypoglycemia interacting with the children's behaviors. Their findings suggest that handling developmentally and age appropriate behavior problems is more difficult in relation to diabetes management.

Common problems such as refusing to eat what is on their plate, or acting up during meal or bedtime has an added stress when you factor in how it will affect diabetes management (Hilliard, Monaghan, Cogen, & Streisand, 2010). All children exhibit these behaviors, unfortunately refusing to eat dinner after being dosed with a certain amount of insulin can lead to harm for a child and leads to hyper vigilance by parents, while the same behavior in a child who does not have diabetes is not as concerning for parents since no element of harm is involved.

While parents with older children report less daily management of diabetes, many parents express concern and fear about letting the child take over self-care (Loding et al., 2008; Marshall, Carter, Rose, & Brotherton, 2009; Smaldone & Ritholz, 2011). This giving up of control was discussed frequently throughout our workshops. Adolescence and transition to independence can be a difficult time for a family raising a child with T1DM (Loding et al., 2008; Marshall et al., 2009; Smaldone & Ritholz, 2011). Parents feared sending children to school because they weren't sure they could trust the school staff, never got away from home because there weren't reliable baby sitters, and even hesitated to relinquish control to the child themselves, especially as some of the children were approaching adolescence. They wanted to give their child more autonomy over the disease, yet were constantly fearful of their children being able to controlling their blood sugars.

While approaching adolescence had the parents concerned, the realities of dealing with very limited options for childcare were weighting on all the families currently. It was mentioned many times in the discussions and on the written questionnaires how difficult it was to find babysitters for just a few hours that would take care of their child with diabetes. Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, and Grey's (2002) research with mothers raising children with T1DM found that only 47% of mothers held part-time jobs compared to 79% of control mothers who worked full or part-time. Of those mothers who no longer worked, all stated they had previously worked but had been unable to continue due to the increased responsibilities of raising a child with T1DM. Within our group none of the mothers worked outside of the home. Two mothers did work part time from their home.

Smaldone and Ritholz (2011) showed that parents felt alone in child care duties when their child had T1DM. Often even extended family was reluctant to baby-sit, and one mother had to pull her son out of daycare when they let him sleep all afternoon and when she got to him his sugar was extremely low (Smaldone & Ritholz, 2011). Parents in our workshops had both positive and negative experiences including extended family in care for their child with T1DM and many family members expressed fear of babysitting a child with T1DM.

The cost of caring for a child with T1DM can be an overwhelming burden. Researchers examined the health insurance experience and out-of-pocket health care costs of families with a child with T1DM, and found most families raising a child with T1DM had health insurance, but out-of-pocket health care costs were 56 % higher than those in the control families without diabetes (Songer, LaPorte, Lave, Dorman, & Becker, 1997). In addition, mean total yearly medical expenditures for people with T1DM was nearly \$10,000, while their control counterparts

(people without T1DM) spent approximately \$3,580 in the same year on medical care (Tao, Pietropaolo, Atkinson, Schatz, & Taylor, 2010).

While the cost of managing T1DM is substantial, many of the parents in our group were interested in cures for diabetes; specifically stem cell research and pancreatic islet cell transplantation. All of these developing techniques are experimental and not covered by insurances if they can be obtained at all. Islet cell transplantation also carries the added risks and costs associated with any other organ transplant such as lifelong immunosuppressive therapy, and the procedure frequently has to be repeated to insure adequate production of insulin (Fiorina et.al., 2008; Monti et.al., 2008).

While the future of diabetes care is rapidly changing and treatment options and cures are being studied, parents raising a child with T1DM have many challenges to face daily. Many of these challenges were discussed in our workshops such as difficulties working with the school system, dealing with health care professionals, emotional challenges of parents, involving extended family, behavior issues of their children, diabetes control as adolescents, child care issues, and cost of treatment were verified by our participants.

Limitations

Study participants were all Caucasian from two-parent families living in a suburban community. Minimal cultural diversity reduces generalization. In addition, study participants were volunteers, and there may be differences between parents who volunteer to participate in research and those who do not. Other limitations included a small sample size which precluded statistical analysis of the Pediatric Inventory for Parents. Conducting only four workshops is also a limitation. If the intervention had been longer would we have seen different results?

Implication for Clinical Practice

This study found that giving parents of children with T1DM a forum to discuss their trials and triumphs and to garner ideas from others living with the same situation, can affect parent stress levels. Establishing the benefits of parental workshops/support groups is an important step in being able to (a) support parents, children and family members; (b) educate families; and (c) establish community education and outreach for families dealing with T1DM.

Although a small pilot study, participants benefitted from interacting with other parents of children with T1DM. These interactions allowed for the exchange of information, parenting strategies, and coping strategies. Nurse Practitioners need to recognize raising a child with T1DM is a challenging and ongoing process that impacts the entire family. Throughout development, different issues will arise that will require adjustments as well as new education and support. Milestones and key transitions in a child's life such as starting school or entering adolescence will change not only management of T1DM, but will also require continued education and support. Improving communication between health care providers and parents raising children with T1DM should be a high priority for NPs which should continue throughout the child's life.

Parents often describe feeling alone, without support even from extended family in raising a child with T1DM. Support groups can lessen this feeling, improve interaction with others, and teach coping skills to deal with daily struggles, as well as provide recourses for parents as their children transition through many stages of life. Groups that involve the entire family have been show particularly successful (McBroom & Enriquez, 2009). Parents and families who establish partnerships with each other and their health care providers, share

responsibilities and collaborate on care, adapt, adjust and feel more capable of daily care regimens (Smaldone & Ritholz, 2011).

Most noteworthy for Nurse Practitioners, was throughout the workshops parents had almost no questions about blood glucose monitoring, usage of pumps, A1c levels or any other daily management issues. All of their comments, concerns and questions focused on the emotional experience of living with diabetes and raising a child with diabetes. Their concerns centered on allowing their children to live normal lives, discipline, implementing self care, involving siblings and extended families and adapting to the ever changing developmental needs of their children. Health care providers tend to emphasize blood glucose control rather than understanding and assisting families in their everyday lives and struggles of raising a child with T1DM (Konradsdottir 2011). This is a tendency that we need to be aware of and as Nurse practitioners, we should take the time to address the needs families have raising a child with T1DM.

Being aware of milestones and transitions in the lives of children with T1DM Nurse practitioners can give guidance and support during office visits and avoid being accusatory or unsympathetic to dynamic changes in the child and the family. During visits NPs can provide valuable education, assistance, and support to parents raising a child with T1DM about common parenting issues. While this open communication between parents and health care providers is important, assisting them in connecting with other parents and families living with the experience of raising a child with T1DM could help reduce feelings of isolation and could provide emotion/social support.

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Table 1
Frequency of Stressors

Appendix A

Person	Emotional		Communication		Medical care		Role Function		Total Frequency	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
#1Husband	36	*34	15	*16	15	*19	26	*20	92	*89
#1 Wife	36	*34	16	*16	16	*19	18	*20	86	*89
#2Husband	43	*37	26	*20	26	*20	28	*14	123	*91
#2Wife	40	*37	21	*20	25	*20	22	*14	108	*91
#3 Husband	39	n/a	27	n/a	22	n/a	23	n/a	111	
#3 Wife	35	36	25	20	23	16	22	19	105	101
#4 Husband	26	n/a	15	n/a	13	n/a	15	n/a	69	
#5 Husband	35	35	20	17	14	13	17	19	86	84
#6 Wife	54	43	25	27	25	23	31	30	135	123
#7 Wife	32	n/a	16	n/a	19	n/a	24	n/a	91	
Average	37.6	36.6	20.6	19.4	19.8	18.6	22.6	19.4	100.6	95.4

Table 2
Difficulty of Stressors

Person	Emotional		Communication		Medical care		Role Function		Total Difficulty	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
#1Husband	58	*33	28	*13	29	*16	33	*17	148	*79
#1 Wife	33	*33	16	*13	15	*16	14	*17	78	*79
#2Husband	47	*41	18	*13	17	*12	22	*12	104	*78
#2Wife	40	*41	14	*13	17	*12	19	*12	90	*78
#3 Husband	39	n/a	23	n/a	25	n/a	18	n/a	105	
#3 Wife	38	42	18	14	21	15	15	20	92	91
#4 Husband	20	n/a	11	n/a	12	n/a	13	n/a	56	
#5 Husband	30	34	15	16	11	12	16	20	72	82
#6 Wife	57	48	27	25	23	21	36	35	143	129
#7 Wife	31	n/a	14	n/a	20	n/a	24	n/a	89	
Average	39.3	38.9	18.4	15.3	19	14.8	21	19	97.7	88

*these post test scores were completed by both parents

Appendix B

PEDIATRIC INVENTORY FOR PARENTS

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. Please complete both columns for each item.

EVENT	HOW OFTEN?					HOW DIFFICULT?				
	1=Never,	2=Rarely,	3=Sometimes,	4=Often,	5=Very often	1=Not at all,	2=A little,	3=Somewhat,	4=Very much,	5=Extremely
1. Difficulty sleeping	1	2	3	4	5	1	2	3	4	5
2. Arguing with family member(s)	1	2	3	4	5	1	2	3	4	5
3. Bringing my child to the clinic or hospital	1	2	3	4	5	1	2	3	4	5
4. Learning upsetting news	1	2	3	4	5	1	2	3	4	5
5. Being unable to go to work/job	1	2	3	4	5	1	2	3	4	5
6. Seeing my child's mood change quickly	1	2	3	4	5	1	2	3	4	5
7. Speaking with doctor	1	2	3	4	5	1	2	3	4	5
8. Watching my child have trouble eating	1	2	3	4	5	1	2	3	4	5
9. Waiting for my child's test results	1	2	3	4	5	1	2	3	4	5
10. Having money/financial troubles	1	2	3	4	5	1	2	3	4	5
11. Trying not to think about my family's difficulties	1	2	3	4	5	1	2	3	4	5
12. Feeling confused about medical information	1	2	3	4	5	1	2	3	4	5
13. Being with my child during medical procedures	1	2	3	4	5	1	2	3	4	5
14. Knowing my child is hurting or in pain	1	2	3	4	5	1	2	3	4	5
15. Trying to attend to the needs of other family members	1	2	3	4	5	1	2	3	4	5
16. Seeing my child sad or scared	1	2	3	4	5	1	2	3	4	5
17. Talking with the nurse	1	2	3	4	5	1	2	3	4	5
18. Making decisions about medical care or medicines	1	2	3	4	5	1	2	3	4	5
19. Thinking about my child being isolated from others	1	2	3	4	5	1	2	3	4	5
20. Being far away from family and/or friends	1	2	3	4	5	1	2	3	4	5
21. Feeling numb inside	1	2	3	4	5	1	2	3	4	5
22. Disagreeing with a member of the health care team	1	2	3	4	5	1	2	3	4	5
23. Helping my child with his/her hygiene needs	1	2	3	4	5	1	2	3	4	5
24. Worrying about the long term impact of the illness	1	2	3	4	5	1	2	3	4	5
25. Having little time to take care of my own needs	1	2	3	4	5	1	2	3	4	5
26. Feeling helpless over my child's condition	1	2	3	4	5	1	2	3	4	5

EVENT	HOW OFTEN?					HOW DIFFICULT?				
	1=Never,	2=Rarely,	3=Sometimes,	4=Often,	5=Very often	1=Not at all,	2=A little,	3=Somewhat,	4=Very much,	5=Extremely
27. Feeling misunderstood by family/friends as to the severity of my child's illness.....	1	2	3	4	5	1	2	3	4	5
28. Handling changes in my child's daily medical routines	1	2	3	4	5	1	2	3	4	5
29. Feeling uncertain about the future	1	2	3	4	5	1	2	3	4	5
30. Being in the hospital over weekends/holidays.....	1	2	3	4	5	1	2	3	4	5
31. Thinking about other children who have been seriously ill.....	1	2	3	4	5	1	2	3	4	5
32. Speaking with my child about his/her illness	1	2	3	4	5	1	2	3	4	5
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing).....	1	2	3	4	5	1	2	3	4	5
34. Having my heart beat fast, sweating, or feeling tingly	1	2	3	4	5	1	2	3	4	5
35. Feeling uncertain about disciplining my child.....	1	2	3	4	5	1	2	3	4	5
36. Feeling scared that my child could get very sick or die.....	1	2	3	4	5	1	2	3	4	5
37. Speaking with family members about my child's illness	1	2	3	4	5	1	2	3	4	5
38. Watching my child during medical visits/procedures.....	1	2	3	4	5	1	2	3	4	5
39. Missing important events in the lives of other family members.....	1	2	3	4	5	1	2	3	4	5
40. Worrying about how friends and relatives interact with my child.....	1	2	3	4	5	1	2	3	4	5
41. Noticing a change in my relationship with my partner.....	1	2	3	4	5	1	2	3	4	5
42. Spending a great deal of time in unfamiliar settings.....	1	2	3	4	5	1	2	3	4	5

Appendix C

What did you find helpful about today's workshop?

What would make these workshops more beneficial?

What topics would you like discussed in a future workshop?

How has attending this workshop impacted your stress level?

What are some of the challenges of raising a child with diabetes?

How has raising a child with diabetes impacted your life?

Do you plan to attend next month's workshop?

Appendix D

Family Information Questionnaire (One per family)

- (1) Today's Date _____
- (2) Family ethnicity _____
- (3) Ethnicity of child with type 1 diabetes (if different from family) _____
- (4) Child with diabetes' birth date _____ Age _____ Gender _____
- (5) Initials of sibling who is participating in the study _____
- (6) Sibling's birth date _____ Age _____ Gender _____
- (7) Please list the initials of the first names of all other children in your family (do not include sibling listed above or child with diabetes)

Name	Male/Female	Age	Birth date (Month/Day/Year)
------	-------------	-----	-----------------------------

- (8) Family Composition: (circle one)
 - 1. Two Parent Family 4. Other Family Type _____
 - 2. Single Parent Family 5. Other adults besides parent living at home? Yes No
 - 3. Step Parent Family 6. If yes, who? _____
- (9) Age of Parents: _____ Father _____ Mother
- (10) How many years of education has husband completed? _____ years
- (11) How many years of education has wife completed? _____ years
- (12) What is husband's current occupation? (job title) _____
Please briefly describe husband's duties _____
- (13) What is wife's current occupation? (job title) _____
Please briefly describe wife's duties _____
- (14) If husband has been employed outside of the home during this past year, has the employment generally been full time or part time? _____
- (15) _____ Number of hours husband works per week.
- (16) If wife has been employed outside of the home during the past year, has the employment generally been full time or part time? _____
- (17) _____ Number of hours wife works per week.
- (18) _____ Husband's religious preference.
- (19) _____ Wife's religious preference.
- (20) What is your total family income?

1. Under \$7000	3. \$15001-\$25000	5. \$35001-\$50000	7. \$75001-\$100000
2. \$7000-\$15000	4. \$25001-\$35000	6. \$50001-\$75000	8. Over \$100000

(21) The medical specialist caring for my child is:

Name: _____
 Address: _____

 Phone: _____

- (22) My child was diagnosed with diabetes in (month/year) _____
- (23) My child has an insulin pump YES NO
 - a. If YES date child started using insulin pump (month/year) _____
- (24) Please describe your child's experience with type 1 diabetes (type of insulin currently taking, challenges with management, etc.)
