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Outcomes and solutions for children and families affected by type 1 diabetes mellitus

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Outcomes and Solutions for Children and Families Affected by Type 1 Diabetes Mellitus

An Honors College Project Presented to
the Faculty of the Undergraduate
College of Math and Science
James Madison University

by Melissa Ann Gray
May 2017

Accepted by the faculty of Honors Interdisciplinary, James Madison University, in partial fulfillment of the requirements for the Honors College.

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Abstract

Caring for children with chronic medical conditions, such as type 1 diabetes mellitus (T1DM) has negative implications for the psychosocial wellbeing of the family. Through this project, the negative affects of T1DM on the family were addressed by the formation of the Life’s Too Sweet: A Workshop for a Brighter Future With Type 1 Diabetes (LTS) event, which creates community support for affected families. During LTS workshops, parents collaborated with each other, while the children participated in fun, educational activities about nutrition, fitness, and overall health in relation to T1DM. Supporting interdisciplinary professionals, such as nurses, social workers, registered dietitians, certified diabetes educators, and exercise science professionals facilitated the event along with students from the James Madison University Students With Diabetes chapter (JMU SWD). The workshops also included inspirational keynote speakers as well as T1DM technology and treatment intervention vendors. Following the second annual LTS workshop, adult volunteers were offered an anonymous survey in order to gain qualitative feedback about the event and their experiences regarding caring for a child with T1DM. Results indicate strong positive feedback regarding the quality and effectiveness of the second annual LTS workshop. Additional analyses reveal that most participants agreed that T1DM prevents them from attaining peace of mind, but also agreed that T1DM can also have some positive impacts on their family. Comprehensively, this project establishes the viability and success of interdisciplinary and community-based intervention efforts in rural areas and validates the recommendation for support and funding for committees to coordinate similar workshops for families affected by T1DM and other chronic conditions.
Background

Caring for a child with a chronic condition adds an additional level of complexity to the daily challenges of supporting one’s family. Chronic conditions typically require constant monitoring and are likely to interfere with everyday family activities. Of the many chronic conditions impacting children and adolescents, type 1 diabetes mellitus (T1DM) is becoming increasingly prominent, especially in children under the age of five (Lipman, 2013). T1DM is a condition in which the pancreas produces little to no insulin, a crucial hormone specifically for carbohydrate metabolism and energy production. Children and adolescents with T1DM are fully dependent on insulin injections and constant blood glucose monitoring for survival. Therefore, families affected by T1DM are burdened with the responsibility of monitoring and adjusting insulin doses to efficiently manage their child’s disease.

Studies on parents and siblings of children and adolescents with T1DM indicate increased stress levels as well as potentially negative psychological effects due to their continuous role in assisting with T1DM management (Northam et al., 1996; Streisand et al., 2005; Whittemore et al.). Additional studies highlight the potential for improved psychological outcomes due to the incorporation of proper coping strategies and support (Grover et al., 2016; Jackson, Richer & Edge, 2008; Jaser, Linsky, & Grey, 2014; Sleeman et al., 2010). Thus, healthcare providers must deliver psychological and social support not just for children affected by T1DM, but also for the entire family.

Clinical support is typically offered to children and families affected by T1DM by means of a therapist or social worker. However, increasing evidence shows that additional social support through online forums, social media, and learning communities can facilitate better coping strategies and improved psychological wellbeing (Balkhi, Reid, McNamara, & Geffken,
2014; Davis & Vitagliano, 2015; Due-Christensen, Hommel, & Ridderstråle, 2016; Petrovski, Zivkovic, & Stratrova, 2015). A variety of online forums, such as Children With Diabetes, Diabetic Connect, and Diabetes Daily, as well as Facebook groups, such as Beyond Type 1, Faces of Diabetes, and Project Blue November have been created to effectively meet this need. Additionally, community support groups exist in most highly populated areas in proximity to large children’s hospitals.
Local Problem

The need for support groups for families affected by T1DM in rural areas has seemingly been overlooked. A request to a local hospital for family resources revealed that only one support community that gathers intermittently throughout the year at the local hospital has been created to meet the needs of the current area. However, the group has been struggling with attendance and is in need of additional support and resources. Efforts to create an inclusive support network in the local community for families affected by T1DM are necessary to address this need.
Program

To further explore and meet this need, we collaborated with a Mid-Atlantic community hospital as well as the James Madison University Students With Diabetes (JMU SWD) club to host an outreach event, Life’s Too Sweet! A Workshop for a Brighter Future with Type 1 Diabetes (LTS). A pilot event, held in November 2015, brought over 20 families together for a community-based workshop that reached over 60 people. The workshop included an inspirational speaker, a vendor fair, small group activities for children, and discussion groups for parents and guardians. This event specifically included the entire family, as parents were encouraged to bring all of their children, and not just their child with T1DM. This was intentional to provide support for the siblings of children with T1DM, as they are also affected and can benefit from education to better understand and connect with the affected sibling. Additional caretakers such as grandparents, aunts, uncles, and guardians were also encouraged to attend the event in order to gain a better understanding of T1DM in the context of this community. The event was free of charge to the families, which was important to reach as many families as possible.

Given the success of the pilot LTS event as well as the positive feedback received, we planned a second annual LTS event to take place on November 6, 2016. The importance of maintaining the event date in November is to highlight the significance of this month as National Diabetes Awareness Month, which is a special time of the year for T1DM families to celebrate their triumphs over such a challenging condition. Utilizing and expanding upon existing resources from the pilot event, we aimed to make the second annual LTS workshop an even greater success. The main goal was to integrate additional community-based organizations and to reach a larger number of families from a broader geographic area.
Objectives

The following list contains the objectives set forth for the current project.

• To learn about the psychosocial effects of T1DM on families and children and to share this information with the T1DM community.

• To address the need for social support by hosting an outreach event that brings affected families together in a supportive and educational environment.

• To create interprofessional collaboration between the JMU community and the surrounding local community to initiate a plan to address the need for education and support.

• To summarize and evaluate the effectiveness of the outreach event and to assess any needed improvements.

• To construct an effective plan to continue the outreach event annually through JMU SWD.
Implementation

Pilot LTS Event

After identifying key collaborators for the creation of the LTS workshop, we began gathering resources to make this event successful. First, we proposed our idea to a local hospital, but the limitations of putting together an event in a corporate location quickly became discouraging. Therefore, we decided to run the event independently with additional support from outside resources. Given the lack of funding from an outside organization, we needed to secure a large space that would hold about 70 people and was also free of charge. By collaborating with the JMU SWD club, we were able to gain access to facilities on the JMU campus that could be booked by the club free of charge. After booking a location for the event, we were able to begin our advertisement campaign. We distributed flyers two months prior to the event to local pediatric offices, pediatric endocrinology offices, representatives for local diabetes management companies, and health coordinators (school nurses, dietitians, etc.), as well as posted the flyer on relevant Facebook pages (Figure 1). We also received funding to run an advertisement in the local newspaper a few weeks prior to the event (Figure 2). Furthermore, we reached out to a variety of motivational speakers until we established contact with an 18-year pilot with T1DM. Since travel was involved, paying for a keynote speaker was the largest expense of the event. However, we provided diabetes management company vendors with a suggested donation amount in order to reserve a table at the event. The total sum of the donations was sufficient to cover the cost of the keynote speaker as well as some of the supplies for the event. One of the companies agreed to provide refreshments as part of their donation. To express our gratitude, we created a poster acknowledging the specific company that sponsored the refreshments (image not included).
Figure 1. Flyer for the Pilot LTS Workshop that was distributed to local families.

Figure 2. Advertisement posted in a local newspaper three weeks prior to the pilot event.
As families began expressing interest about the event, we created an Excel spreadsheet that included information regarding contact information, the expected number of adults, and the ages of children attending. This information was used not only to contact the adults with specific details for the event, but also to determine the expected number of people attending and to divide the children into groups by age. Although it was suggested that attendees RSVP prior to the event, we also noted that walk-ins were welcome.

The final step of the planning process involved creating age-appropriate activities for each group of children for the breakout sessions. The youngest group, children ages 4-7 years old, talked about how it feels when their blood sugars are low and received a brief explanation of ways to identify when they are low. They also learned basic diabetes-related vocabulary words with simple definitions and descriptions. This group was given diabetes-related coloring pages and puzzles to complete during their free time. The next group, children ages 8-12 years old, played a carbohydrate count guessing game and then wrote two negative things about diabetes on a balloon, which was be popped at the completion of the session. They also wrote two positive things about diabetes on a ribbon, which they took home with them as a memory of their experience at this event. Finally, a 25-year T1DM veteran spoke with this group about his experiences with T1DM to encourage them to overcome some of its perceived boundaries and limitations. The two oldest groups, children ages 13-14 years old and 15+, participated in the balloon and ribbon activity and heard from the 25-year T1DM veteran speaker. The older groups then combined to play a diabetes-themed interactive jeopardy game.

On the day of the LTS workshop pilot event, families signed in with their contact information indicating if they would like to be contacted about future events. The commencement of the event included a brief introductory speech that outlined the purpose and
goals of the workshop. The keynote speaker, an 18-year old pilot with T1DM, then delivered a presentation about his journey toward overcoming perceived limitations. The purpose of his presentation was to inspire the children to follow their dreams as well as to communicate to the parents that their children with T1DM have bright, and nearly limitless, futures. Through the speaker sharing his challenges and triumphs, the children heard a real-life perspective on the different ways to overcome some of the challenges posed by living with a chronic condition. For instance, there are severe regulations for pilots with T1DM that our speaker persistently navigated through in order to achieve his dream career. Overcoming those barriers makes him someone to look up to and motivates many to aspire to live in the resilient way that he does.

Following the presentation, families were encouraged to ask questions to transition into a more conversational experience with the speaker.

Following the keynote speaker, the adults and children were encouraged to split up into groups based on the sticker that was previously placed on their nametags. Breakout sessions were formed by dividing the children into groups according to age, which created a supportive environment that allowed for age-appropriate education and activities that facilitated collaboration within the groups. Similarly, the adults were divided into two groups based on the age of their child with T1DM, one group of parents with younger children with T1DM and one group of parents with older children with T1DM. Each of the groups were facilitated by two to three members of the JMU SWD club, who attended a brief orientation prior to the workshop. The students facilitating the activities for the children’s groups helped them gain a better understanding of T1DM through fun activities. Meanwhile, the adult groups shared their personal experiences and opinions regarding different T1DM topics based on pre-specified conversation prompts, such as school and diabetes, helpful diabetes care tips and tricks, and
current diabetes challenges. JMU SWD students held the responsibility to keep the conversation moving and to guide the parents through constructive dialogue. Students were also encouraged to share personal experiences with the parents, providing them with input from the unique perspective of a T1DM college student.

Small group sessions were interspersed with short breaks that allowed the parents to speak with the vendors and to check in with their children. An important aspect of the format of this event was keeping the parents in close proximity to their children to allow for continual diabetes monitoring if necessary. Therefore, the parents were able to relax and focus, knowing that their children were nearby and accessible if they needed to correct a change in their blood sugar levels. During break times, the families were also encouraged to meet and greet with each other with the purpose of creating a close-knit T1DM community. Door prizes donated from various diabetes support companies were also raffled off during this time.

At the conclusion of the event, we played a video, titled Type1Day1, which features inspirational messages from families affected by T1DM worldwide (NLC Creative & Beyond Type 1& Greathouse, 2015). The main point of this presentation was to show families that they are not alone in this constant battle of managing T1DM and that there are people everywhere to provide encouragement and support. The video effectively tied together our main goals for the pilot LTS event by focusing on creating a supportive T1DM community in the local area.

Surveys were distributed to parents at the end of the event to assess the quality of the event and the overall response was highly favorable. In creating the current project, our goal was to recreate this pilot event while making necessary improvements and executing a plan for the continuation of the event in subsequent years.
One result of feedback from the pilot LTS event was the creation of an additional T1DM support initiative that was put forth to foster more individualized support between JMU SWD students and families in the local community. The aim of this initiative, called Friends of JMU SWD, is to connect a JMU SWD member with similar experiences and interests to a child with T1DM. One of the main benefits from a program like this is the flexibility for both the student and the family to plan activities around their busy schedules. This mentorship program is easily adaptable for each student-family pair and can take form in a variety of ways that align with the hopes and expectations of both the student and the family. For some of the pairs, the relationship is fostered mostly through communication via emails and phone calls while others plan specific times to meet to do a fun activity. In all cases, the goal is for the child with T1DM to have a college-aged mentor to look up to and be inspired by. Not only does the student’s relationship with the family benefit the family, but it also provides a sense of connection to the local community for the student.

As part of the continual development of this program, the student mentors are required to provide the coordinator with updates periodically. Overall, there has been very positive feedback from both the students and the families. One area of improvement for this program is to foster better communication and responses from the families that show initial interest in the program but fail to follow up with the student mentors. Amidst the newness of the program, the JMU SWD students have reached about 10 families in the local community and while preliminary feedback has been positive, further research must be done to evaluate and quantify the effectiveness of the Friends of JMU SWD program in addressing some of the negative implications of T1DM.
Second Annual LTS Event

Based on general feedback from the pilot event, we decided to hold the event in a more convenient location and to include dietitians for nutrition education as a key aspect of the event. We also advertised the event much earlier, starting our advertising efforts about three months prior to the event. To create a more professional looking advertisement, we collaborated with the marketing department of a local hospital (Figure 3). Similar to the pilot event, we distributed advertisements to local pediatric offices, pediatric endocrinology offices, representatives for local diabetes management companies, and health coordinators. We also reached out to the families that attended the pilot event via email and posted to a variety of diabetes-related local Facebook groups. Many of the families that attended the pilot event signed up early, as they were looking forward to attending the second annual event.

Figure 3. Advertisement for the second annual LTS workshop that was distributed and posted in a local newspaper.
Locating a speaker for this event was made possible through collaboration with the national Students With Diabetes (SWD) organization. Founder of SWD and former Miss America 1999, Nicole Johnson, volunteered her time to be our keynote speaker. Having Nicole at our event was a great addition, allowing us to advertise that a celebrity and well-known T1DM role model would be present at the event. We also reached out to vendors at a much earlier date than before, contacting several vendors five months prior to the event. In addition to diabetes support company vendor tables, we included display tables at this event to promote additional diabetes resources and the Friends of JMU SWD program. Another addition to the second annual LTS workshop was collaboration with the Morrison-Bruce Center, which is an organization dedicated to promoting a healthy active lifestyle for girls in the community. This organization provided us with volunteers to coordinate active games for the children to participate in during the event. This event was also enriched by the inclusion of a social worker as well as a T1DM “veteran” of nearly 25 years who holds a world record for the highest recorded blood glucose level. Together, these elements were imperative to advancing the development of this program and contributed to the greater success of the second annual event.

On the day of the second annual LTS workshop, we had volunteers stationed around the building to direct attendees to the correct room. This change was made due to feedback regarding the difficulty of locating the room for the pilot event. Additional diabetes-themed decorations were added to the room to make the atmosphere familiar, welcoming, and comfortable for the families. Vendors were invited to set up early, and were encouraged to remain throughout the event to maximize their opportunities to speak with the families. Volunteers attended a brief orientation to get their group assignments and to go over the specifics of the workshop. As the families arrived, they signed in with their contact information and were given raffle tickets and a
colored bracelet indicating which group they would go to for the breakout sessions. They were encouraged to meet and greet with the other families and to visit the vendors and display tables until the event began.

At the start of the second annual LTS workshop, we delivered an introductory speech that provided families with background information about all of our collaborators present at the event. This was an important aspect because there were many different people involved and we wanted to ensure that the families knew the roles of each of them. We introduced our keynote speaker, Nicole Johnson, who began by showing her personal documentary from her pageant days. She spoke about how she has lived beyond the challenges and limitations posed by T1DM to advocate for herself and everyone affected by T1DM. Her speech was inspirational and included many personal stories about how she has faced adversity because of her condition but has overcome many challenges through resilience and her support system. Toward the end of her talk, Nicole invited her daughter up on stage, explaining that among her achievements, having a child has been the greatest of them all. This moment was particularly important, as parents were able to see that their children with T1DM have bright futures including the possibility of having a family. At the conclusion of Nicole’s presentation, families were encouraged to ask questions and had the opportunity to take pictures with Nicole, featuring her Miss America crown atop their heads.

Following the keynote speaker, there was a brief break for the families to visit the vendors and for the parents and children to divide up into their breakout session groups. The main difference between the breakout sessions in this workshop compared to the pilot event was the rotational basis of the breakout session schedule. There were three separate breakout sessions, which allowed for brief breaks in between each, during which parents could check in with their
children, and groups could have time to rotate to the next station. The children physically moved around the room to each activity while the parents remained in small circles with only the moderator changing after each session. The JMU SWD student moderators assigned to each group remained with that group throughout all three rotations.

The parent groups were again divided based on age of their child with T1DM, resulting in three parents’ groups for children ages 4-7 years, 8-12 years, and 13-18 years. One JMU SWD student was assigned to moderate each parent group with the responsibility of maintaining a steady and productive conversation. The moderators blindly drew predetermined discussion topics from a bag, and adults were encouraged to discuss their experiences and questions concerning that particular topic. The student moderator was also encouraged to provide insight regarding their personal experiences with topics that they found particularly relevant to their own journeys. The topics included diabetes technology, burnout, T1DM summer camps, 504 plans and school, T1DM hacks (what tricks have you figured out that make caring for your T1DM child a little easier?), sickness and T1DM, negative stigma, advocacy, insurance, and coping with other medical conditions in addition to T1DM. These group discussions were also facilitated by a social worker that rotated around to each parent group to increase the effectiveness of discussions and to provide input. Another important addition to these discussion groups were parents of JMU SWD students who came to enrich the discussion based on their experiences with T1DM children who are now in college and moving toward adulthood. The information provided by these parents was invaluable, as other families were able to learn from the experiences of college student parents who have experienced several years of successful T1DM management. The inclusion of JMU SWD parents was a great addition to the workshop and will be highly encouraged for future workshops.
While the parents participated in discussion groups, the children were divided into groups that rotated to different interactive educational programs. The rotations schedule ensured that every group had the opportunity to visit each activity, including an age-appropriate nutrition activity and discussion with dietitians, fitness activities with the Morrison-Bruce Center, and a diabetes lifestyle discussion with the T1DM “veterans” (Table 1).

Table 1. Rotation schedule for break out session by age group during the second annual LTS workshop.

<table>
<thead>
<tr>
<th>Time</th>
<th>4-7 years</th>
<th>8-12 years</th>
<th>13-18 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>2:00-2:30</td>
<td>MB</td>
<td>T1DV</td>
<td>D</td>
</tr>
<tr>
<td>2:45-3:15</td>
<td>D</td>
<td>MB</td>
<td>T1DV</td>
</tr>
<tr>
<td>3:30-3:50</td>
<td>T1DV</td>
<td>D</td>
<td>MB</td>
</tr>
</tbody>
</table>

Key: T1DV=T1DM "veterans", MB=Morrison-Bruce Center, D=dietitians

At the dietitian station, the 4-7 year group reviewed My Plate guidelines for healthy eating, using a “smiley face” plate as a model (2017). The smiley face plate contained food groups, such as grains for one eye, protein for the other eye, and fruits and vegetables for the smile with a small circle of dairy for the nose. This information was intended to be simple enough to apply in different settings, such as meals at home. To reinforce these ideas, the children were encouraged to use what they just learned to create their own plate using a blank paper plate and food stickers. The children took their completed smiley face plates home as a souvenir and reminder of how to create a healthy and balanced plate. Handouts with additional information regarding nutrition were also given to the children for them to take home and share with their parents.

The 8-12 year group also reviewed My Plate guidelines before playing an active game to reinforce healthy eating principles. The game was a relay race, with two teams that had to race against each other to quickly and correctly classify foods into categories, such as grain, protein,
dairy, etc. This was an interactive way for them to reinforce their knowledge of food groups, while also building a sense of teamwork among their groups. At the conclusion of the game, the dietitians discussed the results, clarifying corrections to foods that had been improperly classified. This group received the same supplemental handouts as the 4-7 year group for distribution to parents.

The 13-18 year old group sat with the dietitians to discuss healthy snacks with an emphasis of combining both protein and carbohydrates to create a balanced snack that is ideal for T1DM children. Children discussed some of their favorite healthy snacks before receiving handouts containing additional recipe ideas. They also reviewed My Plate guidelines for healthy eating in more detail than previous groups.

The next station was the Morrison-Bruce Center (MBC), where the groups had an educational session followed by one or two activities. The youngest group (4-7) played “Snack Time,” which began with a review of food groups before the children were asked to travel back and forth between a “fridge” to pair items together to create a balanced snack. The goal was to make as many acceptable combinations as possible to teach the children about the importance of variety in their diet. Then they played a game during which a scenario was read before the children were instructed to race to the answer they thought was correct. Examples of some of the scenarios included, “You are at a friend’s house and your blood sugar begins to drop. Which should you choose to quickly raise your BG, juice or candy bar?” and “Is it better to play outside by yourself or with a friend?” Both of these activities encouraged the children to actively move around the room, which was crucial as the importance of exercise was also emphasized at this station.
The middle group (8-12) also played the scenario game, but with more advanced scenarios such as “Which of the following influence your blood glucose levels? Choose all that apply.” Some of the correct answers for this question included sleep and stress, with one of the wrong answers being weather. Another scenario was “At what blood glucose level would it be dangerous to exercise?” with the answer of 350mg/dl noted as the best answer. Following this activity, the middle group played a balancing blood sugar game. First, the group was split into two teams that were given a scenario of having an elevated blood glucose level of 180mg/dl after eating too much cake at a party. The teams were given the goal of hypothetically reducing that blood glucose level by playing games with their friends to reduce the level to 100mg/dl. To do this, team 1 was given “sugar” in the form of a beanbag, which they threw in the opposite direction of the groups. Team 1 formed a circle, which one of their team members had to run around. Each completed lap around the circle lowered the blood glucose by 5mg/dl. Meanwhile, team 2 ran to the beanbag that was previously thrown by team 1. Once the beanbag was in their possession, they formed a single file line and passed the beanbag over-under style until it reached the end of the line. Once the beanbag reached the end, the team 1 runner who was doing laps around the circle had to stop running. Teams switched roles until one of the teams hypothetically reached the goal blood glucose level of 100mg/dl.

The oldest group (13-18) also played the balance the blood sugar game. However, their game was more complex due to the introduction of “chance cards” which would either raise or lower the blood glucose levels based on the different scenarios provided. Examples of chance card were, “Exercise with a friend, blood glucose decreases 5 mg/dl” and “You did not get enough sleep last night! Blood glucose increases 5 mg/dl”. Before moving on from this station,
all groups were given handouts about exercise and T1DM, which were produced by MBC in conjunction with the kinesiology department.

The final station that the groups rotated to was a discussion session with people who have lived with T1DM for over 25 years. Some of the topics discussed with the presenter with the world record included personal experiences with T1DM, low and high blood glucose symptoms, the importance of having friends and family who are there to help when needed, and misconceptions about T1DM. Additional topics covered with the other veterans included the emotional aspects of T1DM, coping strategies for burnout, the relationship between blood glucose levels and emotion, and allowing mental breaks from T1DM to reduce feelings of being stressed or overwhelmed.

Between each rotation, the children were encouraged to check in with their parents, particularly to test blood sugar levels and make any necessary adjustments. The two JMU SWD students moderating each group remained with them and gathered the children following the short breaks between sessions. The moderators were also provided with activities to entertain the children during downtime. The 4-7 year group was provided with diabetes-related coloring pages, find-a-word puzzles, and a twister game. The 8-12 year group was given a ball with age-appropriate diabetes-related and unrelated questions on it for them to pass around to learn more about each other. They were also given suggestions of additional icebreaker games to play as well as a diabetes-related jeopardy game. The 13-18 year group was given a different ball with age-appropriate diabetes-related and unrelated questions on it for them to pass around and answer. As with the previous group, this group was also provided with age-appropriate icebreaker games and diabetes-related jeopardy. However, there was very little downtime between sessions, so the moderators did not make much use of the filler activities. This was
made possible due to the outstanding planning and execution of the contributors who ran the activities at the three different stations.

Following the breakout sessions, the families gathered together for the conclusion of the event. After thanking our vendors, keynote speaker, and all of the contributors who made the second annual LTS workshop possible, we played the same Type1Day1 video that we played at the conclusion of the pilot LTS workshop. Although some of the families had viewed the video during the previous workshop, we felt that it was important to remind them of the need for support for T1DM families through these workshops. After the video, we offered the adults the option to complete an anonymous survey.
Evaluation

An informal, optional, anonymous survey was distributed at the conclusion of the pilot event to receive information about how to improve the event for the following year. Information gathered from these surveys was summarized into areas of improvement that would be addressed in the planning and creation of the next annual workshop. Areas assessed in the survey included overall experience, interest in future events, topics discussed at the event, event logistics, beneficial aspects of the event, advertising, and a comment section for suggesting any additional improvements.

A formal, optional, anonymous survey was offered to all adults in attendance at the conclusion of the second annual LTS event in accordance to IRB protocol No. 17-0252 (Figures 4 & 5). Those who decided to participate were asked to complete the survey in a private location around the room without discussing the information with their spouses, family members, etc. Surveys were kept in a locked box to be securely moved from the event location to a permanent secure location. The goal of the survey was to gain insight on the necessity and effectiveness of workshops like LTS, to gain a better understanding of how T1DM affects families in this community, and to gain information on how to make improvements for future LTS events.
**SURVEY FOR LIFE’S TOO SWEET TYPE 1 DIABETES WORKSHOP**

Instructions: Please complete the questions below **anonymously**. Your responses will be used for an honors thesis research project and to and further the mission of this event.

On the scale below, from “strongly agree” to “strongly disagree”, please respond to the following statements. Place an “X” in the appropriate column (one X per row).

<table>
<thead>
<tr>
<th>Life’s Too Sweet Workshop Evaluation</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I learned something new about type 1 diabetes at the workshop today</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 This workshop helped me connect with community members who are struggling with something I am</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>6 Events such as Life’s Too Sweet could help families affected by other chronic conditions beyond type 1 diabetes</td>
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<td></td>
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<tr>
<td><strong>Personal Experiences</strong></td>
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<tr>
<td>12 I feel that type 1 diabetes has a negative impact on my family</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>13 I feel that type 1 diabetes is challenging, but also has some positive impacts on my family</td>
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<td></td>
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<td></td>
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<tr>
<td>14 I feel that type 1 diabetes negatively affects my social life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>15 I feel that type 1 diabetes prevents me from having peace of mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>16 There are sufficient resources in my local community for families affected by type 1 diabetes</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Figure 4. Optional anonymous evaluation offered at the conclusion of the second annual LTS workshop.*
**SURVEY FOR LIFE’S TOO SWEET TYPE 1 DIABETES WORKSHOP**

How did you hear about this event?

What was the most beneficial aspect of this event/favorite topic discussed?

What other topics would you like to have discussed at a similar event?

Additional Comments:

*Figure 5.* Optional open-ended questions offered as part of the evaluation of the second annual LTS workshop.
Analysis and Results

The survey data were analyzed by transforming the Likert scale data into a numeric scale (1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree). The number of responses was tallied for each individual question and summarized. The percent of each answer relative to the number of responses for each question was also calculated. To gather sufficient information to draw a conclusion about the average response, the median response was calculated for each question (Table 2). The median was calculated to measure central tendency instead of the mean in order to minimize the effect of outliers on the overall response. The median numbers were then transformed back to each respective qualitative value to draw clear conclusions about the central tendency for each question (Figure 6).

The median response for the workshop evaluation questions was either “agree” or “strongly agree.” The median response was “neutral” for T1DM negatively affecting the family and the adults’ social life. The median response for T1DM having some positive impacts on the family and for T1DM preventing the adults from having peace of mind was “agree”. The median for there being sufficient T1DM resources in the local community was labeled “slightly disagree” after being calculated as 3.5, which is directly between the scale for “neutral” and “disagree.”
Table 2. Total responses to survey questions from the second annual LTS event based on 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree. Parentheses indicate the percentage of total responses per question.

<table>
<thead>
<tr>
<th>Question #</th>
<th>Score</th>
<th>Total</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>1</td>
<td>8 (40)</td>
<td>9 (45)</td>
<td>3 (15)</td>
</tr>
<tr>
<td>2</td>
<td>16 (80)</td>
<td>4 (20)</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>18 (90)</td>
<td>2 (10)</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>12 (60)</td>
<td>8 (40)</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>18 (90)</td>
<td>2 (10)</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>13 (65)</td>
<td>7 (35)</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>18 (90)</td>
<td>2 (10)</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>12 (60)</td>
<td>6 (30)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>10</td>
<td>14 (70)</td>
<td>6 (30)</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>17 (85)</td>
<td>3 (15)</td>
<td>0</td>
</tr>
<tr>
<td>12</td>
<td>1 (8)</td>
<td>6 (46)</td>
<td>4 (31)</td>
</tr>
<tr>
<td>13</td>
<td>0</td>
<td>13 (76)</td>
<td>3 (18)</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>9 (45)</td>
<td>5 (25)</td>
</tr>
<tr>
<td>15</td>
<td>4 (20)</td>
<td>10 (50)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>16</td>
<td>1 (5)</td>
<td>6 (30)</td>
<td>3 (15)</td>
</tr>
</tbody>
</table>
Table 3. Qualitative responses to each survey question after calculation of the median.

<table>
<thead>
<tr>
<th>Workshop Evaluation</th>
<th>Median Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I learned something new about type 1 diabetes at the workshop today</td>
<td>Agree</td>
</tr>
<tr>
<td>2 This workshop helped me connect with community members who are struggling with something I am</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>3 I feel that events such as Life’s Too Sweet help my family build a community-based support system</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>4 I feel that event such as Life’s Too Sweet positively impact my child with type 1 diabetes</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>5 I would recommend events such as Life’s Too Sweet to families affected by type 1 diabetes</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>6 Events such as Life’s Too Sweet could help families affected by other chronic conditions beyond type 1 diabetes</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>7 I can use my experiences at today’s event to have a more positive outlook on type 1 diabetes</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>8 The speaker at today’s event delivered a clear and inspirational message</td>
<td>Strongly Agree</td>
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<tr>
<td>9 This workshop helped me connect with educators and families that can help our family in the future</td>
<td>Agree</td>
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<tr>
<td>10 I plan on attending Life’s Too Sweet and similar community workshops in the future</td>
<td>Strongly Agree</td>
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<tr>
<td>11 Overall, this event was well-organized and met my expectations</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal Experiences</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>12 I feel that type 1 diabetes has a negative impact on my family</td>
<td>Neutral</td>
</tr>
<tr>
<td>13 I feel that type 1 diabetes is challenging, but also has some positive impacts on my family</td>
<td>Agree</td>
</tr>
<tr>
<td>14 I feel that type 1 diabetes negatively affects my social life</td>
<td>Neutral</td>
</tr>
<tr>
<td>15 I feel that type 1 diabetes prevents me from having peace of mind</td>
<td>Agree</td>
</tr>
<tr>
<td>16 There are sufficient resources in my local community for families affected by type 1 diabetes</td>
<td>Slightly Disagree</td>
</tr>
</tbody>
</table>
The responses were summarized in pie charts to gather an overall picture of the percentages of each response for different question categories. The “Workshop Evaluation” section responses indicate overall positive feedback about the logistics of the workshop with 100% agreeing or strongly agreeing with the statements in this section (Figure 6).

**Positive Workshop Feedback**

![Pie chart showing workshop feedback]

*Figure 6. Pie chart of the median responses overall for the workshop evaluation section of the survey, which evaluated positive feedback about the event.*

The responses for each question in the “Personal Experiences” section of the survey were summarized based on individual responses. Overall, participants disagreed, strongly disagreed, or were neutral about T1DM negatively impacting their family. Similarly, most adults agreed or were neutral that T1DM is a challenging condition to manage, but also has some positive impacts on their family as a whole. These responses could be due to the sense of strength and accomplishment felt by families that successfully manage such a demanding condition as suggested by the Chernoff, List, DeVet, & Ireys study in 2001. In this study, 80% of participating mothers of children with chronic illness reported positive impacts on their family. Participants agreed, were neutral, or disagreed about T1DM having negative implications for their social life. Most participants agreed or strongly agreed that T1DM prevents them from
attaining peace of mind, implying negative impacts on their mental health. The responses for there being sufficient T1DM support resources in the local community were scattered and inconclusive (Figure 7a-7e).

**Figure 7a.** Percentage of each answer of 13 total responses to the statement “I feel that T1DM has a negative impact on my family.”

**Figure 7b.** Percentage of each answer of 17 responses to the statement “I feel that T1DM is challenging, but also has some positive impacts on my family.”
Figure 7c. Percentage of each answer of 20 responses to the statement “I feel that T1DM negatively affects my social life.”

Figure 7d. Percentage of each answer of 20 responses to the statement “I feel that T1DM prevents me from having peace of mind.”
Figure 7e. Percentage of each answer out of 20 responses to the statement “There are sufficient resources in my local community for families affected by T1DM.”

Given the data collected from the Likert scale portion evaluation, the Second Annual LTS workshop was an overall positive experience for all those in attendance who completed a survey. Overall, participants did not think that T1DM had direct negative impacts on their family, but inversely has some positive impacts. They were neutral about the possibility of T1DM negatively impacting their social life. However, a majority agreed that T1DM prevents them from attaining peace of mind. Participants provided varying feedback about there being sufficient T1DM support resources in their local community, which could be a result of their diverse geographical locations.

Beyond the Likert scale data, open-ended questions provided insight into beneficial aspects of the event as well as suggested discussion topics for future events. Several participants highlighted the inspirational keynote speaker as the most beneficial aspect of the event. Other highlights included meeting other families affected by T1DM, learning more about T1DM management devices from the vendors, speaking with students in JMU SWD, and having an
overall inspirational experience. Some of the topics suggested for future events included the implications for T1DM management throughout the teenage years, managing T1DM along with other chronic conditions, entering the career world with T1DM, and learning more about diet and exercise specifics. Several of the participants indicated that they found out about the event via email or the flyer that was distributed to local health offices. Others found out by word of mouth, through a JMU SWD member, or saw the ad in the newspaper. Additional comments indicated improvements in the Second Annual LTS compared to the pilot LTS event and indicated anticipation for future events. They also provided comments of gratitude for the thought and energy put into the workshop.
Conclusion

Given the overall success of the Second Annual LTS event, as well as research supporting the potential for such efforts to alleviate the negative impacts of T1DM on the family, this project validates the need for the expansion of supportive efforts for families affected by T1DM. Important aspects of such efforts should include inspiring those affected to live beyond their perceived limits, providing an open dialogue for caretakers, including the entire family of the child with T1DM, fostering community, and building supportive relationships among the families. Education is also a key component and should be delivered in a fun and interactive way for the children to become involved in learning more about topics relevant to T1DM. Evaluation is crucial for improvement and further development of these programs. Although evaluations provide insight, the true effects of these events could surpass our ability to survey them, as they provide immeasurable hope and inspiration for a brighter future for these families amidst the, at times, insufferable challenges of T1DM.
References


NLC Creative & Beyond Type 1, & Greathouse, N. (2015). *Type1Day1* [motion picture]. United States: Beyond Type 1. https://beyondtype1.org/type-1-day-1/


