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The Experience of Siblings of Youth with Type 1 Diabetes

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Experiences of Siblings of Youth with
Type 1 Diabetes

Stephanie Miller

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

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ABSTRACT

Experiences of Siblings of Youth with Type 1 Diabetes

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Background. Type 1 diabetes requires intensive management, including blood glucose monitoring, carbohydrate counting and dietary modification, and administering insulin. When a child is diagnosed with type 1 diabetes, family dynamics are often altered as family schedules revolve around care for the child with diabetes. In addition, siblings face unique challenges as they become involved in the care of the child with type 1 diabetes. Therefore, it is important to understand experiences of siblings of youth with type 1 diabetes.

Aims and Objectives. To identify experiences of siblings of children with type 1 diabetes from their own perspectives.

Sample. As part of a larger IRB approved study, 51 children and adolescents ages 8-18 years with diabetes ($M = 13.18$), who have a sibling ages 8-18 years ($M = 12.6$), were recruited from diabetes summer camps and the diabetes clinic at a regional medical center.

Methods. A qualitative descriptive design was used to ascertain experiences of siblings of youth with T1DM using semi-structured, scripted interviews. Interviews were audio recorded, transcribed verbatim, and analyzed for common themes according to qualitative methodology.

Results. Common themes emerging from the data are: (1) knowledge about type 1 diabetes – how it was obtained and what more siblings wanted to know; (2) feelings experienced; (3) sibling relationship – the impact of diabetes on the relationship; and (4) involvement in diabetic care.

Implications. It is important for healthcare providers working with children with T1DM and their families need to be aware of and address the psychological effects of the disease on all family members. While providers cannot alleviate all challenges and fears experienced by siblings of a youth with T1DM, they can make the parents aware of the challenges siblings face, facilitate communication among family members, and help connect brothers/sisters with resources such as education, support groups, and counseling.

Key words: children, chronic conditions, siblings, type 1 diabetes, youth

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Experiences of Siblings of Youth with Type 1 Diabetes

The diagnosis of a chronic illness in a young person can be life changing for the family (Streisand, Mackey, & Herge, 2010). This is because family dynamics may be altered and the overall sense of normalcy disrupted if care for the chronically ill youth dominates the family's focus and alters their routine and way of life (Vanderwerp, 2011). Many chronic illnesses share similar stressors and challenges; however, the constant care and attention required of type 1 diabetes (T1DM), with its daily – even hourly – demands, creates a unique challenge for the family.

Background

T1DM is one of the most common chronic illnesses in young people. In fact, it is estimated that in the United States more than 190,000 youth under the age of 20 have diabetes (Pettitt et al., 2014). An additional 18,436 young people are diagnosed with the disease annually (Centers for Disease Control, 2014).

The cause of T1DM is not completely understood, and presently there is no way to screen for or prevent it (Juvenile Diabetes Research Foundation, 2014). T1DM is an autoimmune disease in which a person's immune system attacks and destroys pancreatic beta cells, responsible for producing insulin, a hormone enabling the body to utilize glucose. Therefore, people with T1DM are dependent on exogenous insulin via injection or an infusion using a pump (Juvenile Diabetes Research Foundation, 2014). Even though treatment options are improving and allowing for better blood glucose control, currently there is no cure.

Managing T1DM requires major lifestyle modifications including dietary changes, carbohydrate counting, blood glucose monitoring, and administering exogenous

insulin (Freeborn, Dyches, Roper, & Mandelco, 2013) in order to maintain good glycemic control by keeping blood glucose levels as close to a normal range as possible without provoking hypoglycemia. Hypoglycemia, defined as a blood glucose level below 70 mg/dL, is a serious complication seen in people with T1DM treated with insulin. It occurs due to a delay in eating after an insulin dose, inadequate carbohydrate consumption for the amount of insulin given, increased activity without decreasing the insulin dose or increasing carbohydrate consumption, or if too much insulin is administered. If not treated quickly, hypoglycemia can lead to seizures and cause irreversible brain damage and even death (McPhee & Papadakis, 2011).

Another potential complication of T1DM is hyperglycemia. When a person with T1DM does not receive sufficient amounts of insulin for the amount of carbohydrates consumed, hyperglycemia results. This is serious because hyperglycemia can cause damage to the microvascular and macrovascular systems, leading to retinopathy, renal disease, cardiovascular disease, peripheral artery disease, neuropathy, and immune suppression (McPhee & Papadakis, 2011). This damage makes T1DM the leading cause of blindness, end-stage renal failure, and non-traumatic lower extremity amputation in adults (Center for Disease Control, 2014.) Because of long-term consequences of hyperglycemia and danger of seizure, injury, and death related to hypoglycemia, caregivers and those living with people with T1DM, including siblings, must have a basic understanding of the management of T1DM.

Siblings

Siblings are bound throughout life by a common family history, which plays an integral part of one's development. The relationship provides an environment for an

individual to learn how to interact with peers, manage disagreements, learn to share, and try on different roles (Abrams, 2009). In addition, siblings can influence one another in both positive and negative ways. Mandleco and McCoy (2012) state:

Older adolescents' involvement in illicit drugs and alcohol, as well as deviant and sexual behavior are predictive of their younger siblings' involvement in similar behavior. In contrast, siblings also provide a buffering effect against challenging experiences such as parental divorce or poor peer relationships (p. 377).

In the case of T1DM, family dynamics are affected as care of the chronically ill youth dominates the family's schedule. As a consequence, sibling relationships can be altered, especially if the typically developing sibling must take on a caretaker role (Graff et al., 2012). Loos and Kelly (2006) found nine of sixteen siblings they interviewed contributed to the care of the youth with T1DM, both physically and psychologically. Wennick and Huus (2012) reported siblings assisted with blood glucose monitoring and motivating the youth with T1DM to follow their diabetes management regimen when their brother/sister "needed a break from testing." Siblings in Herrman's (2010) study discussed the need to watch the youth with T1DM for signs of hypoglycemia and intervene accordingly.

Traditionally, studies explored chronic illness from the parent's perspective as well as the chronically ill youth's perspective (Freeborn et al., 2013), but experiences of siblings of these youth are often overlooked (Abrams, 2009). Since siblings of youth with T1DM can be influenced by their brother's/sister's disease, it is important to understand their perspective. Therefore, the aim of this study is to increase understanding of sibling experiences when living with a young person with T1DM. In

this study siblings of youth with T1DM were interviewed and described and their first-hand experiences and explored their: (a) knowledge of T1DM; (b) feelings experienced by having a sibling with T1DM; (c) perceptions of the effect of T1DM on the sibling relationship; and, (d) involvement in the diabetic care of the brother/sister with T1DM.

Methods

Design

With the use of semi-structured, scripted interviews, a qualitative descriptive design was used to investigate experiences of siblings of youth with T1DM.

Participants

As part of a larger IRB approved study, youth ages 8-18 years ($M = 13.18$; $SD = 3.00$) with T1DM, who have a sibling ages 8-18 years ($M = 12.6$; $SD = 2.8$) were recruited from diabetes summer camps and the diabetes clinic at a regional medical center (Table 1). Birth order of participants was distributed with 20 older siblings, 23 younger siblings, and three siblings of the same age. Most participants were Caucasian and came from two-parent families with a household income greater than \$50,000.

Study Procedures

After obtaining IRB approval, parental consent and sibling assent were obtained. Siblings then participated in an audio-recorded interview, at a private place in their homes for approximately one hour. The interviewer used an interview guide, adapted from Van Riper (2000), which sought responses to family experiences, demands, problem solving, coping, appraisal, and general well-being. Content of the interview guide were grouped into five categories: awareness, feelings, having fun, helping, and advocacy.

Probing questions (Table 2) were added if necessary. Siblings of youth with T1DM were asked to respond to all of the interview statements.

Data Analysis, and Interpretation

All interviews were transcribed verbatim and entered into NVIVO9 for data storage and management. The interviews were initially categorized under themes of awareness, feelings, having fun, helping, advocacy, and then a free response for participants to identify the best and hardest thing about living with sibling with T1DM. The interview started with the interviewer reading a statement (see Table 2) and participants were asked to respond “yes” or “no”; the interviewer then followed-up with probing questions, where appropriate.

For the yes/no statements I calculated the percent of yes/no responses to identify commonalities. I also compared the percentages between older and younger siblings to look for notable differences between the two groups.

In analyzing the responses, I used a process of qualitative data analysis that incorporated open, axial, and selective coding (Neuman, 2006; LaRossa, 2005). Using open coding, I initially read through the interviews and wrote down and identified the major themes that emerged for each broad category (knowledge, feelings, relationship with sibling, and involvement in sibling’s diabetic care.) In the axial coding phase, questions/answers that overlapped were collapsed into broader categories. These categories were narrowed to better reflect findings. Some questions were excluded as they did not relate to diabetes, were leading, and/or the answers were not related to diabetes. For example, siblings’ responses to the statement “It makes me sad when people tease [sibling]” did not relate to diabetes. The answers did not indicate that their

sibling's disease had anything to do with how they would feel about their sibling being teased and, in general, were not revealing.

The responses from the free response were included in the themes where they most appropriately fit. Throughout the analyses process, I constructed an audit trail that detailed how I defined the themes (Gilgun, 2005).

In the selective coding phase, I selected quotes from each category that best reflected common feelings and findings between the participants, which were used in reporting the results. To provide context, additional information was bracketed to clarify ambiguous statements.

Results

Common themes that emerged upon analysis of the data were: (a) knowledge; (b) feelings; (c) relationships; and (d) involvement in diabetic care.

Knowledge

The first theme to emerge was knowledge about T1DM with subthemes of how that knowledge was obtained and areas where siblings wanted additional teaching about T1DM. Ninety-one percent of siblings reported parents talked to them about diabetes when the youth with T1DM was diagnosed. The teaching done by the parents constituted most of the sibling's education about T1DM. Only a few siblings said they received additional teaching from healthcare providers or institutions. Subthemes included what participants had learned from their parents about T1DM as well as information about T1DM they wanted to know more about.

What parents told siblings about T1DM. When describing what parents told them about T1DM, several participants mentioned a few topics. The most common topic

was signs and symptoms of hypoglycemia and how to treat it. One nine-year-old sibling described what her parents taught her about hypoglycemia, “They’ve told me that when she’s [sister with T1DM] babysitting if she ever passes out I need to see if I can wake her up or call 911, or go over to the neighbors and call them [parents] on my mom’s cell phone.”

Some siblings had a basic understanding of the pathophysiology of T1DM. An eighteen-year-old sister demonstrated this: “I know that insulin is made by your pancreas and that’s what her [sister with T1DM] body is not producing automatically anymore, so that’s what her shots do.” A seventeen-year-old sister said, “I know that DM is caused because of the pancreas, how it can’t produce insulin any more. And so insulin controls that glucose, so that’s why she [sister with T1DM] has to take insulin shots.”

Siblings also reported their parents talked about short and long-term consequences if the brother/sister with T1DM did not adequately control his/her blood sugar. One eighteen-year-old sibling was told of her younger sister, “...if she doesn’t take care of herself, she’ll die, or she’ll end up getting really sick. Just that if she takes care of herself, she could live. We also talked about if she doesn’t take care of herself she won’t be able to have kids.” Another eighteen-year-old participant’s knowledge of consequences of poor glycemic control was demonstrated when she wanted to know, “How long it takes for things to kick in, like if she [sister with T1DM] doesn’t take care of herself, how soon she’ll lose her eyesight, or her kidney will go bad, or if she doesn’t take care of herself for so long, if it would affect her permanently.” A fourteen-year-participant learned from her parents, “...if you don’t take care of it [T1DM], you could lose a finger, toe, like seriously a leg.”

Some siblings were told they needed to help the brother/sister with T1DM manage their disease, as demonstrated by a fifteen- year-old participant who reported his parents told him, "...I need to help him [younger brother] regulate [blood sugars]." A sixteen-year-old participant was told by her parents, "...I am the oldest...[it is] my responsibility to help out and make sure she [sister with T1DM] blood tests 'cause she gets a little spacey sometimes about that."

What siblings want to know about T1DM. Sixty-five percent of siblings felt like they knew "a lot" about T1DM, but 91% wanted to know more about the disease. When asked what more they wanted to know, most siblings wanted more information about managing T1DM. Hypoglycemia was especially concerning for many siblings. A nine-year-old sister asked, "Like, what'll I do if [brother with T1DM], like, passes out or something? I want to know what to be able to do, 'cause you know, I want to help him." An eleven-year-old male participant said, "I ask them what to do in some situations and usually like if he's [brother with T1DM] high what to do and if he's low what he should eat. What has lots of carbs?" A nine-year-old sister said, "I ask them questions like if they're [sister with T1DM] high, I ask them how much insulin they'd need so I'd get it down, how much in case they're really high. I ask if they're low, what kind of snacks to give them."

Another common question from siblings was what causes T1DM. A thirteen-year-old participant asked of her younger sister, "I just asked where it came from, how did she get it, is it contagious, or how she got it..." A fourteen-year-old sister asked, "How does it work and how did he [brother with T1DM] get it and is it contagious?" Some siblings' desire to know what causes T1DM was fueled by the fear of developing

the disease themselves, as demonstrated by one sixteen-year-old sister's comment, "I would want to know who, if you were born with the gene for T1DM, because it's, like, a genetic thing. I would like to know when is the age that it usually comes up, the age group because I have the gene...when it's most likely, the average." A ten-year-old participant spoke as if his developing T1DM was inevitable, "I would like to learn how to take care of myself. How to, um, not struggle when I get tests or insulin, and I gotta get used to shots."

Finally, siblings wanted to know about a cure for the disease. A twelve-year-old sister asked, "If they are starting to get a cure, and how close they are and stuff." Similarly, a seventeen-year-old female participant said, "I would like to know how close they are to finding a cure and what the steps are to finding a cure for that." An eleven-year-old brother spoke of finding a cure in the future: "I'd like to learn more about how we can find a cure and what kind of medicines to use for that cure. And hopefully someday I will be able to make a cure."

Feelings

A second theme to emerge was participants' feelings with regard to their brother/sister having T1DM, with subthemes of pity, frustration, resentment, and pride. Participants were asked different questions to assess feelings that accompanied living with a brother/sister with T1DM. As mentioned before, siblings were concerned for the youth with T1DM and the possibility of short-term and long-term negative health consequences. Along with concern, participants expressed a variety of emotions directly related to T1DM, including pity, frustration, and resentment directed toward their

brother/sister. On a positive note, the majority of participants also expressed feeling pride in the way their sibling had dealt with T1DM.

Pity. When asked if they felt sorry for their brother/sister with T1DM, 82% answered “yes”. Many youth cited insulin shots and finger pokes as the reason they felt sorry for the youth with T1DM. A fourteen-year-old brother said, “Yah, I hate needles, dude. He [brother with T1DM] has to, like, poke his finger and stuff. He’s got a pump and they stick a needle like that big into him [indicates size with fingers], it’s scary!” A nine-year-old sister said, “...she [sister with T1DM] says it hurts when she gets her palm pinched...”

A source of pity mentioned as often as shots and finger pokes was dietary restrictions. A fifteen-year-old said of his younger brother, “...he can’t do exactly what other people can do, and he’s got to watch himself. Like he can’t just eat things, like candy and stuff, I guess he could but he probably shouldn’t...He’s got to always remember that he has to take care of himself.” A fourteen-year-old male said simply, “Cause he [brother with T1DM] can’t eat stuff that he wants to.” An eleven-year-old brother had similar sentiments, “Cause it would really stink to have diabetes and she [sister with T1DM] can’t eat everything that I can.”

Frustration. The majority, 84%, of participants admitted to becoming frustrated with their brother/sister with T1DM. When T1DM was the source of their frustration, participants cited mood swings related to blood glucose levels as the reason. One fourteen-year-old sister said, “She [sister with T1DM] gets really kind of cranky when . . . it [blood glucose] gets high. She just goes through mood swings and you can tell if she is high or low. And it gets frustrating when she just doesn’t feel like giving insulin...”

Another sibling, eleven years old, said of his sister, "...she kind of acts ornery like she doesn't feel good, that's when she is low or high or something." A nine-year-old sister noticed, "...when she's [sister with T1DM] low she is kind of mean and...when she's high she acts really hyper."

Some siblings became frustrated when they felt like the brother/sister with T1DM used their condition to get out of family responsibilities. A fourteen-year-old brother said, "Older sisters, they're really obnoxious. Sometimes she has to check her blood and I say it's just an excuse so she doesn't have to go help." Another participant said of his sister, "She kind of milks the system [imitating youth with T1DM]... 'I'm sick, I can't do this, or I can't 'cause I'm not feeling good.'"

Siblings also became frustrated when the entire family was affected because the youth with T1DM did not manage diabetes the way it should be managed. An eighteen-year-old sister explained,

She [sister with T1DM] likes to eat normal candy and just say, oh I can just give myself a shot, or I can just go low for it. She just likes to do things she's not supposed to. She likes to sleep in late and that makes her go low, but she obviously doesn't remember it, so it doesn't affect her. She just doesn't realize how much of an impact it has on the rest of the family.

A seventeen-year-old sibling had similar feelings toward her sister,

I feel bad when she'll neglect checking herself. When she forgets her kit I get frustrated. And when she allows it to become a problem between her and my dad. She knows it's a disease and knows it's serious, but she allows the situation to become an issue between her and my dad.

Resentment. Less than one-third of participants resented the extra time their parents spent with their brother/sister with T1DM. A twelve-year-old participant denied being mad about his parents spending more time with his brother with T1DM, "...I know that he has a disease and he needs to be taken care of first..." Another twelve-year-old felt differently about his sibling's diabetes, "I just feel like I'm invisible. I can't be seen."

Sometimes resentment came from the perception that youth with T1DM got special treatment because of their condition. A fourteen-year-old sister said, "...she [is] just always grumpy and always yelling at me...I will get mad back and go to my parents and tell them she has no right to do that and they will tell me to just let it slide, because of her diabetes. It bugs me sometimes." A fourteen-year-old brother commented, "[It] seems like they [parents] are more lenient [with sister with T1DM], will let her off easier because she has diabetes."

Pride. Eighty-six percent of participants expressed feeling pride in their sibling with T1DM. Several times that pride stemmed from how the youth with T1DM dealt with diabetes as demonstrated by a fourteen-year-old sister, "I know that it would be hard to have diabetes and I respect her [sister with T1DM] for...getting through it." Another participant, also fourteen years old, said of her sister, "I am proud of her with how she has dealt with the diabetes and stuff, I think it's pretty cool." A twelve-year-old participant said of her brother, "He's strong and he's brave, because I couldn't give shots and he just does it, just like pokes it in and takes it out like that, it would take me forever to do that."

When asked how they answer questions about their sibling's diabetes, participants focused on what the youth with T1DM can do instead of limitations related to the disease. A thirteen-year-old brother said, "She's [sister with T1DM] not different than anyone else, she's the same, so I explain that to them, like she's a normal kid, she doesn't have any differences only that she is diabetic." Another thirteen-year-old said of his brother, "...he can do things...better than most people can, as well as people can." A fourteen-year-old sister explained, "I just tell them that she [sister with T1DM] can pretty much do everything that everyone else can do, but only a few things get in her way. She still runs, she goes running every day. She still eats certain foods that you wouldn't think a person [with T1DM] would eat."

Relationship with Sibling with T1DM

The third theme revealed to what degree T1DM affected the relationship between the participant and their sibling. Participants were asked about their desire to spend time with their brother/sister with T1DM. Ninety-four percent stated they chose to spend time with the youth with T1DM and 98% said they enjoyed doing things with their brother/sister with T1DM. Participants were then asked why they spent time with the youth with T1DM. Participant's desire to spend time together did not seem to be influenced by T1DM. A seventeen-year-old participant said of spending time with her sister, "It goes beyond having to do with diabetes and has to do with the role I play as her older sister. I choose to do things with her because that's my obligation as her older sister."

Often, participants' desire to spend time with their brother/sister with T1DM was influenced by common interests between and the participant and their sibling, as well as

by availability of playmates. A thirteen-year-old participant said of her sixteen-year-old brother, “He’s fun. We play sports and we have the same interests.” A fourteen-year-old participant said, with regard to time spent with her sister with T1DM, “...usually when I don’t have any friends to play with, or don’t want to hang out with my friends.”

When asked if the brother/sister with T1DM was invited to play with the sibling and his/her friends, 47% answered “yes.” Again, T1DM did not appear to be a factor in this finding. Personality difference between the youth with T1DM and participants friends, as well as gender difference, often factored into whether participants invited them to play together. When asked if she liked to include her brother [thirteen-years-old] when she played with her friends, an eleven-year-old participant said, “No, because they’re girls.” The same participant stated that she did not invite her brother to play with her friends “Because my friends [and brother] are just different.” All participants said they wanted the youth with T1DM to be included in family activities and as one eighteen-year-old sister explained, “She [sister with T1DM] does everything we do.”

Involvement in Diabetic Care

The final theme revealed was the participant’s involvement, both physical and psychological, with their sibling’s diabetic care. This theme revealed a sizable difference in participants responses based on their birth order as more older siblings reported involvement in their brother’s/sister’s diabetic care than younger siblings. In both older and younger siblings, involvement in care was manifest in the form of protectiveness and responsibility for the brother/sister with T1DM.

Protecting the youth with T1DM. When participants were asked if they were protective of the youth with T1DM, 78% of older sibling participants said “yes”

compared to 64% of younger sibling participants. The following example shows how an older participant, twelve-years-old, is protective of her 10-year-old sister:

Sometimes someone asks if I want this [treat] and [she] can't have some and I say, no, that's okay. Then I say, do you have a fruit roll up or something like that, just so [she] can have it and they say, "Are you doing that just 'cause [sister with T1DM], can't have it?" And I say, "Yeah, because she can't have this." So I explain what she can have.

This protectiveness was also demonstrated by an eighteen-year-old participant's response when she said, "I make sure she [twin sister with T1DM] eats on time - make sure she doesn't do things she's not supposed to."

To contrast, when asked if he felt protective of his brother with T1DM, a twelve-year-old participant said of his sixteen-year-old brother, "Not really, we are at different schools and stuff, and I am the younger brother and he is the older brother."

Being responsible for youth's well-being. When asked if they were responsible for making sure the youth didn't get hurt or in trouble, 73% of older siblings said "yes" versus 50% of younger siblings. The thirteen-year-old sister said of having a nine-year-old brother with T1DM, "...when I was in sixth grade, whenever he would get low at recess or something they would come and get me out of class to go and help him..." An older brother, also thirteen years old, said of his twelve-year-old sister, "...when me and her are the only ones home, [I] make sure that she has her testing kit wherever she goes and that she comes home early or on time and that she can do everything she needs to...get a snack."

Fewer younger siblings reported feeling a sense of responsibility toward their older brother/sister with T1DM. A nine-year-old sister stated, “I don’t really feel that way ‘cause he’s the older brother. He’s supposed to be doing that for me...” Another sibling, fourteen years old, said of his twin sister, “Only if...my parents aren’t around, or my older brother or older sister aren’t around.”

Discussion

The purpose of this research was to delve into the feelings and experiences of youth living with a sibling with T1DM by obtaining first-hand accounts from this population. Themes emerged about their perspectives as their interviews were analyzed.

First, the theme of knowledge about T1DM revealed most of the participants received diabetic education from their parents and there was very little to no formal education from healthcare providers. This was consistent with findings of previous studies (Loos & Kelly, 2008; Wennick & Huus, 2012). Many participants were taught basic pathophysiology of T1DM; however, most parental education centered on recognizing hypoglycemia and what participants should do in such a case and the consequences of poor glycemic control.

Most participants stated they wanted to know more about managing T1DM, which is similar to findings of other studies (Herrman, 2010; Wennick & Huus, 2012). Participants especially wanted more information on their role for treating hypoglycemia. Many participants wanted to know how their brother/sister developed T1DM and the chances that they would develop the condition themselves, similar to findings in other studies (Hollidge, 2001; Ventura, 2012; Wennick & Huus, 2012).

Second, several emotions experienced were common to participants, namely fear and concern, pity, and frustration. Fear for the youth with T1DM was expressed by most of the participants, especially concern about death related to hypoglycemia, supporting previous research (Herrman, 2010; Hollidge, 2001, Loos & Kelly, 2008; Wennick & Huus, 2012). Participants also expressed concern for their brother/sister's future and worried that they would not know what to do in an emergency. Most participants stated that they felt sorry for their sibling with T1DM. As with previous studies, participants reported that they felt sorry because of the pain their brother/sister experienced from finger pokes and insulin injections (Herrman, 2010; Wennick & Huus, 2012). Participants in this study also expressed pity because of dietary restrictions imposed on their brother/sister.

Participants commonly reported frustration with the child with T1DM. As with previous studies, mood swings, related to hyperglycemia and hypoglycemia, were especially frustrating for participants (Herrman, 2010; Loos & Kelly, 2008). Participants also expressed the belief that the young person with T1DM used their disease as a means to get out of tasks and responsibilities, which added to their frustration. A final source of frustration identified was contention caused between family members when the young person with T1DM failed to adhere to their diabetes care plan, also seen in previous studies (Herrman, 2010; Loos & Kelly, 2008).

Feelings of resentment and jealousy among siblings of youth with T1DM have been mixed in previous studies. Hollidge (2001) found that participants denied feeling resentful or jealous toward the child with T1DM. Participants from the Loos and Kelly (2008) and Abrams (2009) studies reported feeling left out and neglected. Herrman's

(2010) participants reported feeling left out, but those feelings were somewhat negated by their relief of not having T1DM themselves. In this study, most participants denied resentment of the extra time parents spent with their brother/sister with T1DM. Of those who admitted to resentment, most vocalized that they understood the necessity of additional time and attention required by their parents to care for their brother/sister's condition. However, resentment toward their brother/sister arose when participants were told by their parents to let bad behavior and mood swings related to blood glucose levels "slide". This phenomenon led participants to conclude that their parents were more lenient with and gave special treatment to the child with T1DM, similar to findings by Loos and Kelly (2008).

Third, themes related to the relationship between participant and brother/sister with T1DM included both positive and negative effects on the sibling relationship. Similar to previous studies, the relationship between participants and the child with T1DM were negatively affected when poor adherence to diabetic care caused contention in the family (Herrman, 2010; Loos & Kelly, 2008). In addition, Wennick and Huus (2012) also found participants identified ways having a brother/sister with T1DM had positively influenced their relationship – citing a greater appreciation for their sibling and for life in general.

Their brother/sister's medical condition did not seem to influence whether participants wanted to spend time with their sibling. The degree to which participants spent time with the child with T1DM was based more on the availability of playmates and whether the siblings shared common interests. As would be expected, participants

who were close in age and the same gender reported spending more time with their brother/sister with T1DM.

Finally, themes emerging about the degree participants were involved in the diabetic care of their brother/sister included physical involvement as well as psychological support. Participants took on more of a caregiver role with the child with T1DM. Older participants in this study more often expressed a sense of responsibility for the well-being of the brother/sister with T1DM, as with other studies (Herrman, 2010; Hollidge, 2001). Similar to previous studies, participants did not administer insulin to their brother/sister but helped out in other ways (Herrman, 2010; Loos & Kelly, 2008; Wennick & Huus, 2012). Participants made sure the brother/sister had his/her diabetic supplies and reminded their brother/sister to check their blood glucose levels and to eat snacks when appropriate. They also monitored for hypoglycemia, offered emotional support and motivation for the child with T1DM, and acted as a resource of information for people not familiar with T1DM.

In summary, much of these findings are supported by previous research, but some findings added to data currently available. For example, this study revealed specifically what participants wanted to know about T1DM. Additionally, we learned the extent to which T1DM affected the sibling relationship and when it became a source of frustration for siblings. Previous studies reported mixed findings regarding siblings' feelings of resentment toward the young person with T1DM; this study offers additional data to this phenomenon as well as why participants felt resentment when they did. This additional information is valuable for healthcare providers in order to provide anticipatory guidance to siblings as well as parents.

Clinical Recommendation

Healthcare providers (HCP) working with young people with T1DM and their families need to be aware of and address the psychological effects of the disease on all family members. While HCPs cannot alleviate all challenges and fears experienced by sibling of a youth with T1DM, they can help parents become aware of the challenges these youth face, facilitate communication among family members, and help connect the brothers and sisters with resources such as education, support groups, and counseling.

HCPs should encourage parents to fully inform siblings of the youth's condition (Ventura, 2010) and involve them in formal diabetic education. Not only should siblings of youth with T1DM receive developmentally appropriate instruction immediately after the diabetes diagnosis, teaching should be ongoing, adding to existing knowledge as siblings grow and their understanding matures (Roper et al., 2009). In this study, participants received little to no formal education about T1DM at the time of their sibling's diagnosis, and nearly all participants wanted to know more about the disease. Abrams (2009) observed that lack of information and understanding of their sibling's condition lead to confusion and distortion. As with our findings, this distortion led siblings to feel responsible for their brother/sister's condition and to worry about the youth's future. The HCP can help support the parents to set boundaries and establish roles appropriate for siblings and therefore alleviate a heavy burden upon the young person.

HCPs should counsel the family to have open dialogue soon after the young person's diagnosis. This reinforces the message that communication is encouraged and is useful (Abrams, 2009). Studies have demonstrated siblings of youth with chronic illnesses often internalize their feelings (Abrams, 2009; Fleary & Heffer, 2013; Hoolidge,

2001; Ventura, 2010; Wennick & Huus, 2012), and our findings were no different. Participants reported feeling fear, guilt, anger, and resentment. Allowing siblings the opportunity to talk about their feelings with their family normalizes these reactions and provides family members a way to work through complex feelings and to better cope (Abrams, 2009). Family and individual therapy can be very beneficial for helping siblings to cope and should be recommended by the HCP when appropriate.

HCPs should encourage siblings of youth with T1DM to participate in group events with other siblings of youth with T1DM (Ventura, 2010). Parents may be unaware of resources available to siblings of youth with T1DM and may need guidance from the HCP to identify local programs such as sibling support groups, camps for siblings of youth with T1DM, as well as events aimed at families of youth with T1DM.

Participation in group events allows siblings of youth with T1DM to know that many of their peers are going through similar circumstances and can help them feel less isolated (Abrams, 2009).

Finally, online support groups are available for a variety of groups and provide a way for people to connect from all around the world. However, online support groups are not readily available for siblings of youth with T1DM. An online support group for these youth could increase accessibility to support for those who do not have resources in their communities, and should be encouraged.

Limitations

This study was designed to explore experiences of siblings of youth with T1DM; however, there were some limitations. Participants were volunteers, and, as such, may have characteristics not representative of the general population. Participants were also

recruited from diabetes summer camps and an urban diabetes clinic and may have access to resources not available to other families caring for a youth with diabetes.

Another limitation is a homogenous sample (Table 1). Ninety-eight percent of participants were Caucasian, 67% of families had an income greater than \$50,000 per year, and 92% of participants came from a two-parent family living in a western state of the United States. As such, this sample may not accurately represent experiences of siblings of youth with T1DM with different demographics. Despite these limitations, the findings in this study highlight the importance of addressing the needs and challenges experienced by siblings of youth with T1DM.

In light of our findings, future research is needed to evaluate the effectiveness of the above-mentioned interventions. For example, surveys could be administered to siblings of youth with T1DM before and after attending a support group/activity for this group to measure outcomes. Additionally, different programs available to siblings of young people with T1DM should be evaluated and compared to determine the most helpful and appropriate resources for these youth. Future research should also explore if demographics affect the sibling experience by including a more heterozygous population.

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Appendix A

Table 1 *Demographic characteristics of participants and their families*

	Characteristics	Number (<i>n</i> =51)
Participant	Mean age (SD)	12.63 (2.79)
	Gender	
	Male	23
	Female	28
	Birth Order	
	Older Sibling	20
	Younger Sibling	28
Family	Same Age	3
	Household income/year	
	<\$25,000	5
	\$25,000-\$50,000	10
	>\$50,000	31
	Missing data	5
	Ethnicity	
	White	49
	Black	1
	Missing data	1
	Composition	
Two parent family	47	
Single parent family	3	
Missing data	1	

Appendix B

Table 2 *Sample interview statements and follow-up questions by category*

Interview Statements	Probing Questions
Knowledge	
I know a lot about T1DM.	What do you know about T1DM?
I would like to know more about T1DM.	What more would you like to know?
Feelings	
I feel sorry for brother/sister.	Why?
Sometimes I get frustrated with how brother/sister acts.	What are some examples?
Participation in Sibling's Care	
I am responsible for making sure brother/sister does not get hurt or in trouble.	Why do you feel that way?
I come up with ideas of how to help brother/sister.	What ideas have you thought of?
Relationships	
I choose to spend time with brother/sister.	Why or why not?
What is the best thing about living with brother/sister?	
What is the worst thing about living with brother/sister?	
