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Parents Advising Parents: Raising a Child with Type 1 Diabetes

Becky Jean Rasmuson

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

Parents Advising Parents: Raising a Child with Type 1 Diabetes

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Background and Purpose: Children diagnosed with Type 1 Diabetes face significant challenges in the day to day management of their disease. Parents play an important role in supporting children at every stage of their lives and helping them transition to independence in the management of T1D. The purpose of this study was to learn from parents who have raised their children with T1D to adulthood and identify strategies for parents who are currently raising a child with T1D.

Methods: Using a biographical method, a qualitative design, two in-depth interviews with open-ended prompts were completed with purposively selected parents of children with Type 1 Diabetes (T1D) who have grown into adulthood (18 parents, 36 interviews). The first interview invited participants to share their experience raising a child with T1D. The second interview asked specific questions about challenges, things that went well, things that didn't go well and advice for parents currently raising a child with T1D. Qualitative content analysis was used.

Results: Analysis of the data identified recommendations for parents currently raising children with T1D. Advice for the parents included, 1) Parental attitude toward diabetes will be reflected in the child – Keep it positive, 2) Learn as much as you can about diabetes, 3) Find a good diabetes provider – Make your endocrinologist your best friend, 4) Don't make diabetes the definition of the child – treat them as normal, 5) Empower self-management – Teach them along the way then step back and let them take over, 6) Be your child's advocate , 7) Find support – Formal or informal, 8) Listen to your child – Don't judge.

Conclusions and Implications: Nurses and nurse practitioners can share strategies identified by parents that were helpful in raising their child with Type 1 Diabetes.

Keywords: Type 1 diabetes mellitus, insulin-dependent diabetes, parents, advice, school, healthcare provider, parent-child relationship

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TABLE OF CONTENTS

Abstract.....	ii
Acknowledgements.....	iii
List of Tables	vi
Parents Advising Parents: Raising a Child with Type 1 Diabetes	1
Background	2
Research Questions.....	4
Methods.....	4
Participants and Settings.....	5
Research Design.....	7
Results	8
Parental Attitude toward T1DM will be Reflected in the Child – Keep it Positive	8
Learn as Much as you can About T1DM	9
Find a Good Diabetes Provider – Make Your Endocrinologist your Best Friend.....	10
Don't Make Diabetes the Definition of the Child – Treat Them as Normal	11
Empower Self-Management – Teach Them along the Way.....	12
Be your Child's Advocate	14
Find Support – Formal or Informal	16
Listen to Your Child - Don't Judge.....	17
Discussion and Clinical Implications.....	19

Limitations	23
Conclusion.....	23
References.....	24

LIST OF TABLES

Table 1 <i>Participants</i>	6
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Parents Advising Parents: Raising a Child with Type 1 Diabetes

Every day approximately 50 children under 20 years of age are diagnosed with Type 1 diabetes mellitus (T1DM) in the United States ("National Diabetes Statistics Report: Estimates of Diabetes and Its Burden in the United States," 2014) Newly diagnosed children and their parents face the monumental task of learning complex skills including insulin dosing and administration, blood glucose monitoring, and carbohydrate counting (Jönsson, Lundqvist, Tiberg, & Hallström, 2015; King, Berg, Butner, Butler, & Wiebe, 2014). Major lifestyle changes are required for both the newly diagnosed individual and family members as an intense medical regimen becomes a part of daily life. In addition to these physical and mental tasks, children with T1DM and their parents may experience emotional and psychosocial distress and strained parent-child relationships (Dashiff, Riley, Abdullatif, & Moreland, 2011; Jönsson et al., 2014). These challenges extend to the entire family (Marshall, Carter, Rose, & Brotherton, 2009) and evolve over time as children mature to adulthood and responsibilities shift in managing long-term health needs (King et al., 2014).

Regardless of the age of the child with T1DM, the complex nature of managing this disease requires parental involvement in the daily tasks of glucose monitoring, medication administration and, for older children, decision making regarding insulin dosing, exercise and carbohydrate intake (Hanna, Weaver, Stump, Guthrie, & Oruche, 2014). Parents become experts in their child's care and as advocates they interface with the extended family, community, school, and medical providers (Driscoll et al., 2015; Herbert et al., 2015; Smaldone & Ritholz, 2011). As children move into adolescence and become more independent in managing the daily tasks of diabetes management, parent participation remains important. In fact, studies indicate glycemic control in adolescents with T1DM is better when parents are involved. (Berg et al.,

2013; King et al., 2014). However, negative attention from parents such as nagging and criticizing can contribute to poor glycemic control (Luyckx et al., 2013; Palmer et al., 2011).

Despite the fact that parents play such an integral role in the success of diabetes management, little research has been conducted with parents whose children with T1DM have grown into adulthood. Because these parents are no longer involved in the day-to-day management of their children's disease, they have a distinct perspective that is an important area of research. The aim of this qualitative, descriptive study is to gain a greater understanding of the challenges of raising a child with T1DM and effective management strategies from the perspective of parents whose children with T1DM are now adults.

Background

Autoimmune destruction of insulin-producing cells in the pancreas causes T1DM (Gan, Albanese-O'Neill, & Haller, 2012; Herold, Vignali, Cooke, & Bluestone, 2013). Without appropriate production of insulin, glucose cannot enter the cells to provide energy. As a result, glucose builds up in the bloodstream leading to hyperglycemia which causes thirst, frequent urination and blurred vision (Tansey et al., 2016). Over time hyperglycemia damages small and large blood vessels leading to complications such as retinopathy (Hautala, Hannula, Palosaari, Ebeling, & Falck, 2014), end-stage renal disease (Afkarian, 2015), cardiovascular (Bradley et al., 2016) and peripheral arterial disease (Huysman & Mathieu, 2009), and other serious destructive processes (Amutha et al., 2017). Furthermore, in order to get needed energy, the body metabolizes fat giving rise to the buildup of ketones in the bloodstream which induces nausea, vomiting, dehydration and can lead to diabetic ketoacidosis (DKA) (Szypowska et al., 2016). Left untreated, DKA can cause cerebral edema and may lead to coma and death (Ješić et al., 2013).

To treat T1DM, insulin must be administered by the child or family members, either by multiple daily injections or by continuous pump infusion with a goal of maintaining blood glucose levels within an optimal range (Gan et al., 2012). To dose insulin appropriately, children or family members have to monitor blood glucose levels and food intake, particularly carbohydrate intake, throughout the day. Maintaining appropriate blood glucose levels is difficult due to complex interactions of carbohydrate, fat and protein digestion; physical activity; stress; and other factors. Administering too much insulin can result in hypoglycemia leading to confusion, loss of consciousness, and seizures. Left untreated, hypoglycemia can cause irreversible brain damage or death (Little et al., 2014).

Research indicates that parents of children with T1DM often feel overwhelmed and anxious about managing a disease with such serious implications (Viaene, Van Daele, Bleys, Faust, & Massa, 2017). Parents of both young children and of adolescents report fear of hypoglycemia and its potential associated complications as a major stressor (Haugstvedt, Wentzel-Larsen, Aarflot, Rokne, & Graue, 2015; Hawkes, McDarby, & Cody, 2014). Parents also indicate worry over long-term complications of hyperglycemia and frustration with the inability to maintain blood glucose levels within a target range (Trast, 2014; Vanstone, Rewegan, Brundisini, Dejean, & Giacomini, 2015; Wysocki, Buckloh, Antal, & Lochrie, 2011). Lack of confidence in the ability of school, daycare personnel (Driscoll et al., 2015; Herbert et al., 2015) and even extended family members to manage T1DM adds another level of stress when parents rely on these individuals to care for their child. This can lead to parental feelings of grief, isolation, and sadness (Smaldone & Ritholz, 2011).

As youth naturally become more autonomous, conflict between adolescents and parents over diabetes management is common and has been correlated with treatment non-adherence

(Hilliard et al., 2013; Luyckx et al., 2013). Parents often differ from their adolescents in perceptions of the adolescent's competency in managing diabetes and find it difficult to relinquish control of diabetes management (Butner et al., 2009). Supporting children as they become independent in their disease management is an important part of the developmental process but knowing how to best encourage independence is a challenge for many parents. It is indeed important, therefore, to gain a greater understanding of the challenges of raising a child with T1DM and effective management strategies from the perspective of parents whose children with T1DM are now adults. No other published literature was found involving parents who have raised children with T1DM to adulthood.

Research Questions

1. What were some of the challenges faced by parents when they retrospectively reported on raising children with T1DM?
2. What were some of the effective management strategies used by parents when they retrospectively reported on raising children with T1DM?

Methods

After obtaining approval from the university's institutional review board, we used purposive sampling to recruit participants to be interviewed. Inclusion criteria included parents who raised a child(ren) diagnosed with T1DM as a child or adolescent and who have now reached adulthood, age 18 and older. In order to recruit participants, adults with T1DM who participated in a previous research study and members of a T1DM club at a university campus in the intermountain west of the United States were contacted and asked to forward information about this study to their parents. Other participants learned about the study by word of mouth.

Informed consent was obtained from all participants included in the study. After participating in the study, participants were sent a thank you card and \$20 for each interview completed.

Participants and Settings

A sample of 16 mothers and 2 fathers ranging in age from 44 to 69 years ($M=54.88$) were enrolled in the present study. Participants had a total of 22 children (one mother and father of the same child were interviewed separately) and four of the participants had 2 or more children with T1DM (See Table 1). Children of the participants ranged in age from 18 to 36 years ($M=26.18$) at the time of the interview. Age of the children at diagnosis ranged from 13 months to 16 years ($M=8.95$) and they had been diagnosed with diabetes from 8 to 35 years ($M=16.4$) at the time of the interview. None of the participants in the study had T1DM. Interviews took place at a location of convenience for the participant, most interviews were conducted by phone.

Table 1
Participants

Pseudonym	Parent	Age of parent at the time of interview	Gender/age of child(ren) at diagnoses	Age of child at time of interview	Number of children in the family	Birth order of child with diabetes
Sandra	Mom	58	F – 6 y	18	5	5
Helen	Mom	59	M - 13 months	36	5	1
Kevin	Dad	53	M - 2 y 6 m	26	4	3
Scott	Dad	56	F- 14 y	23	5	4
Kathy	Mom	54				
Ellen	Mom	49	M – 16 y	25	5	2
			F – 13 y	22		3
Ruth	Mom	49	F – 16 y	26	10	1
			F – 15 y	24		2
Dorothy	Mom	58	F – 13 y	24	2	2
Jane	Mom	44	F – 12 y	20	4	4
Linda	Mom	46	M – 5 y	19	4	3
Marilyn	Mom	60	F – 12 y	34	5	1
Pamela	Mom	53	F – 11 y	20	5	4
Debra	Mom	62	F – 3 y	25	6	5
Margaret	Mom	69	F – 8 y	27	10	10
Janice	Mom	52	F – 5 y	27	4	1
			F – 2 y 4 m	25		2
			F – 2 y 10 m	23		3
Kelly	Mom	46	M – 8 y	22	5	1
Barbara*	Mom	60	F – 11 y	36	6	1
			M – 12 y	32		2
Teresa	Mom	60	F - 10 y	26	6	6

*A third child was diagnosed with T1DM at age 19

Research Design

This qualitative study used the biographical method in which researchers collect retrospective accounts of a person's life for analysis (Miller, 2003). This method was appropriate for learning from this group of parents who were able to reflect upon their experience of raising a child with T1DM. Two in-depth interviews were conducted with each participant. The first interview was unstructured in order to not limit the topics discussed by the participants. The first interview allowed the participant to answer the prompt "tell me about raising your child(ren) with type 1 diabetes." Interviewers used additional prompts such as "tell me more about" or "can you explain that further" but the participant chose the topic.

A previous research study identified the concerns of parents who were currently raising a child with T1DM and questions for the second interview were developed based on those concerns. The second interview allowed the interviewer to seek clarification of any concerns from the first interview and to explore specific topics of interest in depth by asking the following questions: a) tell me about when your child(ren) was diagnosed with type 1 diabetes?; b) what challenges do you remember? (prompts: management, family members, school system, friends); c) how did challenges change over time? (prompts: elementary, middle school, high school, transition to adulthood); d) what things did you do that worked well?; e) what things did you do that you don't think worked well?; f) what do you wish you had done?; g) what would you do differently?; h) what advice do you have for parents who are currently raising their child with type 1 diabetes?

Interviews, which were digitally recorded, were conducted by a graduate nurse practitioner student and research assistants who were undergraduate nursing students with a basic understanding of T1DM and diabetes-related tasks. The digitally recorded interviews were then

transcribed verbatim and analyzed independently by members of the research analysis team, including a researcher with a Ph.D. in nursing, a graduate nursing student, and, two undergraduate nursing students. The team met frequently to identify themes and subthemes until consensus was reached through discussion. Data were then entered into NVivo 10 software to aid in thematic analysis and exemplars were identified. Recurrence of themes was recognized both within and across interviews.

Results

Parents who have raised children with T1DM were eager to share their experiences in hopes of helping others who are currently facing this challenge. Eight major themes were identified from the advice shared: a) Parental attitude toward diabetes will be reflected in the child – Keep it positive; b) Learn as much as you can about T1DM; c) Find a good diabetes provider – Make your endocrinologist your best friend; d) Don't make diabetes the definition of the child – Treat them as normal; e) Empower self-management – Teach them along the way; f) Be your child's advocate; g) Find support – Formal or informal; and, h) Listen to your child – Don't judge.

Parental Attitude toward T1DM will be Reflected in the Child – Keep it Positive

Thirteen of the 18 participants expressed the importance of keeping a positive attitude when living with a child who has diabetes. Kevin (all names are pseudonyms), father of a child diagnosed at age 2 ½, said, "first of all don't freak out, nobody wants to become diabetic but in the past, it was a death sentence and it is not anymore...you can live a full and happy life." Ruth, whose two teenage daughters were diagnosed within the same year, said, "remaining positive or not showing worry, like we can take care of this, it is going to be okay" was important. She

stated, "They always sense your stress or your concern, and they can see that no matter what age they are."

Janice, mother of three daughters diagnosed at ages 2 years 4 months, 2 years 10 months and 5 years of age explained:

The parent attitude is the most important thing in this whole equation because the attitude you have is the attitude your child will have. And even if it's not the attitude you really have, it's the 'fake it 'til you make it thing.'" If I had a "poor me" attitude I cannot imagine where my kids would be now.

Ellen, mother of a daughter and a son both diagnosed as teenagers cautioned:

You get people all out of the woodwork calling you to give their two cents of advice and I learned early on I only wanted positive people around me. People would call me and say, "This is the most horrific thing that you will ever go through" and I didn't want that. It's not ignoring the negative complications which can occur, it's just we [chose] not to dwell on that.

Learn as Much as you can About T1DM

Participants discussed the need for initial training regarding the diagnosis and treatment of T1DM, but also emphasized the need for continual learning. Kevin explained, "there [are] always new things coming out on it, so a lot of things that we did right was the training...then...refresh it every 5 years or so, to be retrained." Sandra reported, "We attended yearly lectures on upcoming advancements in blood sugar control and things that [were] down the road to try and give us some perspective and I think that really helped."

Written materials in addition to formal classes and lectures were another source of information. Ruth shared, "I tried to read anything and everything" and Sandra encouraged

parents to “read and learn as much as you can about it on your own so that you’re on top of things.”

Two of the participants felt that they should have learned more. One mother, Marilyn, wished she “had done more study, especially while [her daughter] was going through this as a teenager. As a girl going through puberty, that had a lot of effect on what was happening to her blood sugar. I didn’t understand that as well as I should have.” Kathy shared, “I wish I would have been more educated. The more educated you are, the better you can help them.”

Find a Good Diabetes Provider – Make Your Endocrinologist your Best Friend

The importance of having a strong partnership with a healthcare team was discussed by most of the participants. Many of the parents stressed the need for an endocrinologist. Kevin advised:

Make sure you find a pediatric endocrinologist...be persistent and be a little bit skeptical whenever you are working with your regular [general practitioner] or regular hospital emergency room. They are really good people and everything, but, this is kind of outside most of their training.

He further emphasized:

The endocrinology unit, they knew that you were with them for a long-time relationship, not just for a one-time relationship, and they knew how parents and kids and all of this worked. The best thing that ever happened to us was to get connected up with the children’s hospital and get in an endocrinology unit that specifically deals with [T1DM].

Ellen shared, "My advice to [the] newly diagnosed child and family is to make your endocrinologist your best friend." She added, "You find a [healthcare provider] (HCP) you click with because you are gonna have this relationship with that [person] for years."

Participants also talked about other members of the healthcare team that were an important source of support to them and their children. One mother, Marilyn, stressed:

I think one of the things that is really important is to have a good supportive medical team. We were up at [the children's hospital] and besides having a [HCP], there was also a dietician that worked with us and a social worker. I think that's something that is very important for parents to know - that you can get services like that that can help you.

A few of the parents discussed the need to change HCPs. Barbara, mother of three children with diabetes, shared that her oldest daughter "had one [HCP] at first that she just really didn't like, so we just switched. We just knew that it was a bad personality mix and we just switched to a different one." However, Jane felt that she didn't have a choice with her daughter's HCP. She said:

We went to the hospital. We were assigned [an HCP]. Then we were given an appointment with her after. I did not have the feeling that I could really make a change if I wanted to or needed to...we didn't have a choice in the matter. And I see that frustration a lot with other parents of younger T1Ds especially. They're not necessarily happy with the HCP...but, they don't know that they really have the option to make a change. I wish that somebody had told me that I had a choice.

Barbara said, "Don't be afraid to change [HCPs]. Don't be afraid to keep looking if what you're doing isn't the best thing for your children. Because children change, [HCPs] change."

Don't Make Diabetes the Definition of the Child – Treat Them as Normal

All 18 participants indicated that children with T1DM should have as normal a life as they can. Scott, a father, shared "she just wanted to live as normal of a life as possible, and, thus

we've treated her that way. I think that's the best thing we could've done as parents." Janice, mother of three daughters with diabetes, shared that she had two rules:

- 1) There is nothing you can't do because you are diabetic; and,
- 2) There is nothing you can get away with because you are diabetic.

She further clarified, "Don't let diabetes limit what you do. Always ask yourself, 'How can I make this work? What do I need to do?'"

Barbara indicated: "You can find plenty of parents who hover over their children and don't let them live their lives because of their diabetes, but, it's not a handicap, it's just an annoyance....or just something you have to live with." Dorothy encouraged, "If they have a dream of what they want to be, just help them figure out how they are going to do that. Help them dream with diabetes." Kathy advised, "If you're raising a child with type 1 diabetes...try to give them the confidence and the power to have as much of a normal life as you can. And don't let a medical issue ever be an excuse or a way to get attention or create other issues."

Dorothy indicated that when her daughter was diagnosed with diabetes "it forever altered her, that she wasn't herself anymore, she was just diabetes...She treated her diagnosis with a great deal of shame and that was probably our biggest obstacle...It was mostly a whole journey and helping her come to understand that her whole identity wasn't diabetes."

Helen summed it up with this advice, "Don't make diabetes the definition of the child. If you learn a lot about it and are prepared then you can deal with the diabetes, but, focus on the child's feelings outside of the diabetes."

Empower Self-Management – Teach Them along the Way

Being able to manage diabetes independently is an important milestone for children diagnosed with T1DM and most participants discussed ways in which they supported their

children in gaining the skills needed to manage their diabetes. Many of the children diagnosed as adolescents were encouraged to perform the major tasks of testing blood glucose levels and injecting insulin from the time they were diagnosed. Ruth, mother of two daughters diagnosed as teenagers indicated:

They just kind of took charge. They knew how their body felt, they could feel if they were starting to go high, starting to go low, they would check their sugar...I guess we were just always there to support them and to help them.

Kathy, whose daughter was diagnosed at age 14, shared, "The first little while I would go up [to school]. She was really good at shots and I would go up and take lunch...until she learned...how to carb count and what to eat."

Margaret, the mother of a daughter diagnosed at age 8, indicated,

For three days they taught me and her how to do it. And they told her "This is your disease. You must learn to control it. This is not mom's disease. And so from the beginning, you have to give yourself your own shots." I couldn't believe it. Thank goodness they trained us right because it made her responsible instead of me.

For children diagnosed at a young age, parents all indicated the need to help them learn to manage their disease. Kevin, father of a son diagnosed at 2 ½ stated, ". " He shared:

Right from square one, we got him doing as much of it as possible. So he was 2 ½ when he was diagnosed, so obviously he [was] not doing much at that point, but, it would start with, "Okay go get your blood sugar before dinner and the stuff out...and then Okay do your blood sugar by yourself." I would say by 5 years old he was doing that himself."

Sandra, the mother of a daughter diagnosed at age 6, shared, “We tried to give her responsibilities to do at her own level. We tried as she got older, little by little, to give her more and more responsibilities so she’d be doing it all by herself, obviously.”

Janice, the mother of three daughters, said:

We began teaching them to manage their own disease. When they were diagnosed I had two goals. One was to help them adjust to it so that they were happy people, and two was for them to move out of my house.

She further indicated, “I had to teach them how to manage the disease, not just on the chemical level, but on the mental and emotional level as well.”

Debra whose daughter was diagnosed at age 3 indicated mixed feelings:

I [felt] so bad that she has this disease, so, I’d be like, well, I’ll measure, I’ll count, but, then she won’t learn anything. So I’d be like, oh I need to back off and give her that experience and give her the feeling of “You did it. Look at that, you did a great job and your blood sugar is good two hours later because you measured and you decided the amount you needed.”

Linda, mother of a son diagnosed at age 5 advised, “I wouldn’t be so much of a helicopter. You have to teach them, teach them how to take care of their diabetes. Don’t do it all yourself, teach them along the way.”

Ellen shared, “[It is] kind of like a child on a bike with training wheels and then you kind of let them go without training wheels and hope they do okay.”

Be your Child’s Advocate

Several of the parents of children with T1DM referred to themselves as advocates for their child or described roles in which they advocated for their child. There were different

settings in which this role occurred, but, the most common setting was in the schools. Kelly explained:

I would send out a letter or an email to all his teachers explaining what he needed. And if he needs to go to the bathroom, you need to let him go, and if he is low you need to let him drink juice during class... He just needs to take care of his business and don't slow him down because he knows what he is doing. And so I was his advocate that way because I had to be.

Many participants indicated that there were no dedicated school nurses and most teachers and administrators were unfamiliar with T1DM. Parents felt responsible for educating teachers and school administrators. Teresa shared, "My husband went into the classroom when [our daughter] was in elementary and explained her situation so people weren't wondering why she was going out of the classroom or why [she was] checking her sugar levels." Kelly shared, "I had to be the one to educate the teachers at the school. I was never very comfortable with that, but, I made sure that they all knew what was going on." Most participants indicated that they would go to the school at the beginning of each year to meet with teachers, coaches, school secretaries and other educators.

Another situation in which parents acted as advocates for their children was in the healthcare setting. Debra shared that her child received care at a large children's hospital. She stated, "There is a huge diabetic group there and...we were lost in the numbers we felt...the doctor doesn't even know us, but, that is okay, we got through it...I was her advocate."

Janice discussed the difficulty of dealing with her insurance company to get needed medication approved. She said, "You have to learn and you have to be your own advocate. You cannot depend on the rest of the world to do it."

Jane advised parents, “One thing that’s really important to remember that I wish that somebody had told me is that I am my child’s advocate and that it’s up to me to stand up for them and speak up for them because nobody else is going to.”

Find Support – Formal or Informal

Parents discussed the importance of finding support from both informal and formal sources. Many of the parents indicated that they found support from other parents who were further down the road with diabetes. Sandra remembered:

At the beginning, there was a woman that had a type 1 diabetic son and I picked her brain a lot. And that was good. I’m not a real big one for...group sessions...but it was nice to just have a person that I could just run into.

Dorothy shared:

[I] was so grateful for the people that came to my house and talked about stuff...people I could call and they would tell me, “Oh, I got this scale” or “Here is how a pump would work.” So I would say reach out and get involved.

Kevin recalled:

One of our friends said, “I know somebody else that has a kid that has diabetes,” and this was early on, and so my wife contacted these other people...it was good for her to have somebody else to talk to about it.

Barbara shared:

You accumulate other diabetic friends when you have it, and, so as something new would come out, the parents would talk and we’d say, “Well, have you tried that?” And I think that is where we learned about the CGM, the continuous glucose monitor.

She advised, “Find people who also have it, who you feel are living with it in a good way.”

Parents also discussed formal diabetes support through organizations. Debra commented, “My advice is to find someone who will be that cheerleader in your life, and typically another diabetic parent, so we hooked up with JDRF [Juvenile Diabetes Research Foundation] early.”

She also shared:

I got really involved with JDRF outreach programs. When somebody would get diagnosed I would go. It was my therapy...the hugest blessing to me would be to go to someone and say, “I know how you feel, let me talk to you, let me be your friend. Call me in the middle of the night if you need me.”

Jane emphasized, “Find a support group. Find somebody else that you can ask questions of and bounce things off of because you are not always going to get ahold of a doctor.” Although not available when she was raising her daughter, Jane shared, “I love this particular T1D Facebook page, even though my daughter is an adult. I just glean all kinds of information from it. Finding support that way is a huge deal...A place to go, a forum like that is fantastic.”

Listen to Your Child - Don't Judge

A topic that was emphasized by a few parents was the importance of nonjudgmental communication between parent and child in regard to diabetes management. Those who talked about this felt strongly about it, especially as some regarded this as something, that in hindsight, they wished they had done differently.

Linda wished that she had not “gotten mad” at her son when blood sugar readings were high. She stated, “I wish I would have never done that to him...it wasn't really in his control how his body reacted.” Dorothy lamented, “I put into her head a lot of shame and guilt.” She explained:

There are just so many factors that factor into what your blood sugar is...there is not a formula for perfection and that began to crush her. It was like every time she tested and was crazy off – but that could be emotion or hormones or her period, exercise, whatever, you know, just makes the formula not work. It made her feel like it was a bad, bad grade, that high number. So she just began to not check. She didn't want to know. She didn't want a bad grade. And the key...with that whole issue is just a number, just information.

Dorothy further advised:

Don't attach the bad judgments when you're talking to your child about it. Try and be very calm and not attach those values, terms, as you're treating the number and as you help them through that...Even the terms that we use, "Oh, were your numbers good or were they bad?" It's like a judgment. It's like a condemnation. That was really good for us to learn not to do that.

Pamela advised, "They have to be able to make some mistakes without it getting too intense," and Teresa shared, "If her levels were high or if I noticed that something was off I'd say, "Hey, are you feeling okay?" or, "How are your levels today?" You know, I wouldn't get after her."

Janice explained that her daughters were more resolved to manage their diabetes when no judgment was attached to their A1C or blood sugar levels:

I figured out that checking [blood sugar levels] gives them much better...resolve than telling them that their blood sugars are bad, or that their A1C is bad because I found that if they would check, they'd actually do something about it. We rewarded the checking...We didn't care what the numbers were.

She further clarified, “Those numbers – you have about as much control over them as the doctor does. Your success is measured in the things you’re doing.”

Sandra advised parents, “Listen to their concerns... they’re going to have struggles and just be willing to adjust as they go. They’re going to go through difficulties, you know, just expect that. Because I didn’t realize that her struggle [was] mostly emotional.”

Discussion and Clinical Implications

Parents in this study had years of combined experience raising a child(ren) with T1DM and offered a different perspective from previous studies because they are no longer involved in daily management as their children are now adults. Despite individual differences in these parents’ experience, common themes were found in the advice offered to parents who are now raising a child with T1DM. Understanding what was helpful to these parents can inform healthcare providers in ways to advise and support parents who are currently raising a child with T1DM.

Research indicates that adolescents with T1DM, whose fathers and mothers were resolved with their child’s diagnosis, had better self-management behaviors and exhibited less internalizing and externalizing problems (Goldberg & Wiseman, 2016). Participants in this study felt that their attitude toward their child’s diagnosis affected the child’s attitude, and advised parents currently raising a child with T1DM to keep it positive, stay calm, and, let your child know that it is going to be okay. According to research, acceptance of the diagnosis of T1DM leads to better metabolic control (Scholes et al., 2013) and a positive attitude toward T1DM among adolescents has been reported as a protective factor for glycemic control (Lord, Rumburg, & Jaser, 2015).

Treating the child as normal was important to these parents. Participants recognized that diabetes required vigilance but made accommodations to allow their children to participate in normal activities. Studies indicate that seeking normalcy for both the individual with T1DM and the family is important (Babler & Strickland, 2015; Marshall et al., 2009). Research involving adults with T1DM confirms that these individuals felt that diabetes did not define them nor limit their activities as long as they managed their disease (Freeborn, Dyches, & Roper, 2017). As families seek normalcy for their child with T1DM, HCPs can share tips for managing diabetes during physical activity, travel and other situations.

Multiple studies have addressed the transition of responsibility for diabetes management from parent to child, and researchers have advocated a collaborative relationship between parent and child through the adolescent years (Dashiff et al., 2011; Hanna, Dashiff, Stump, & Weaver, 2013; Spencer, Cooper, & Milton, 2013). Participants in this study discussed the importance of empowering their child to become independent in diabetes management and emphasized starting at an early age and making the transition of responsibility a process. Likewise, a gradual, developmentally appropriate transition of responsibility for diabetes-related tasks has been proposed by previous researchers (Coffen, 2009; Spencer et al., 2013).

Parents and children need to work as a team when making decisions about diabetes management, and nonjudgmental communication is the key to collaboration. Parental, especially maternal, negativity and criticism in relation to diabetes management are associated with poor adherence to treatment and poor glycemic control (Iskander, Rohan, Pendley, Delamater, & Drotar, 2015). Conversely, positive maternal communication, especially in preadolescence is strongly associated with more frequent blood glucose testing as the child moves into adolescence (Iskander et al., 2015). Recognizing the many variables that can affect blood glucose levels

helped participants in this study to be less critical and less emotional in their response to elevated blood glucose levels (Brown, Jiang, McElwee-Malloy, Wakeman, & Breton, 2015; Kilbride et al., 2011).

Due to the complex nature of T1DM, ongoing education is critical for parents. Basic training presented at diagnosis is geared toward survival and focused on diabetes management tasks such as blood glucose monitoring, insulin administration, and carbohydrate counting. Moreover, this initial education is presented at a time when parents are often emotionally distraught (Ayala, Howe, Dumser, Buzby, & Murphy, 2014; Rankin et al., 2016). Participants shared the need for ongoing education in order to understand the complexities of diabetes and to be aware of new advancements in treatment modalities (Albanese-O'Neill, Schatz, Bernhardt, & Elder, 2016; Beran & Golay, 2016). Incorporating ongoing training into visits with the HCP is important both for the child with T1DM and for parents.

Many of the participants in this study discussed the need for support beyond their medical team from someone who had personal experience with T1DM as they adjusted to life with diabetes. Having a veteran parent of a child with T1DM who could offer advice and support following their child's diagnosis was important. According to research, some parents have found peer parent support helpful, while other parents reported that the advice received from veteran parents was not helpful and at times contradicted the advice of their diabetes provider (Rankin et al., 2016). Presently, online diabetes communities provide diabetes information and peer support for parents as well as individuals with T1DM, but, the risk of misinformation has been identified by researchers (Hilliard, Sparling, Hitchcock, Oser, & Hood, 2015; Weitzman et al., 2011). Formal support groups such as JDRF and the ADA have online support groups and JDRF offers

outreach volunteers to support newly diagnosed families. HCPs should provide referrals to these and other trusted sources.

Participants in this study felt that most general practitioners were not up to speed with treating T1DM and recommended specialty care through a pediatric endocrinologist or diabetes specialty clinic. Previous research indicates better outcomes in children treated by specialists as opposed to generalist offices (Zgibor & Orchard, 2004; Zgibor et al., 2000), but, a shortage of pediatric endocrinologists (Vigersky et al., 2014) and long distance travel to access a provider can be barriers for some families. Nurse practitioners and physician assistants that specialize in diabetes management have greatly increased access to specialty care for diabetes and will continue to fill a need in the future (Valentine, 2014). A current trend in providing diabetes specialty care is the use of telemedicine which has been shown to be as effective as a face to face visit and may fill the need for families in rural settings (Smith, 2016; Wood et al., 2016).

Parents in this study described many roles in which they advocated for their children with T1DM, including educating school teachers and coaches, navigating the healthcare system and negotiating with insurance companies. For parents of children with chronic disease, research has identified many roles and responsibilities beyond typical parenting. Parents fill critical roles as “care coordinators, medical experts and systems advocates” (Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009, p. 303). Many of the participants in this study viewed this responsibility as part of their role as parents, however, it is probable that some parents of children with T1DM will not be comfortable or capable in these roles. Medical home or family-centered practices can provide care coordination to help families with school, insurance or other issues and help mitigate the impact of T1DM on the family (Katz et al., 2012).

Limitations

There are limitations to this research study that should be noted. The sample of participants were all Caucasian and 95% were married. Additionally, of the 22 adult children with T1DM, 20 were described by their parent as currently having average to excellent health with only one of the adult children reported to have diabetes-related complications and one other adult child having nondiabetes-related health complications. It is possible that participants whose adult children were not in current good health were less likely to participate. A potential limitation to the study was that eight different research assistants conducted the interviews. In all but three cases, the participant was interviewed by the same research assistant for both the first and second interview.

Conclusion

Helping parents and children have a positive experience as they adjust to a new diagnosis of T1DM can set the foundation for successful disease management throughout the individual's life. Even with recent advances in blood sugar monitoring and insulin administration, T1DM remains a complex and challenging illness. Children who are diagnosed with T1DM and their parents need the support and advice of HCPs as they adjust to lifestyle changes imposed by T1DM. Integrating diabetes management into everyday life can be overwhelming, but, parents in this study offered a positive perspective and sound advice to parents currently raising a child with T1DM.

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