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Perceptions of parenting children with type 1 diabetes diagnosed in early childhood

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Abstract

Introduction—To explore perceptions of psychosocial adaptations in parenting young children with type 1 diabetes (T1DM) from diagnosis through childhood.

Method—Fourteen parents of eleven T1DM children diagnosed at ≤ 5 years participated in semi-structured interviews. Data were analyzed using content analysis.

Results—Significant themes were: *Diagnostic Experiences: Frustrations, fears and doubts:* Parents described inadequate diagnostic experiences with pediatricians where concerns were minimized and sometimes delayed diagnosis. Although hospitalization occurred abruptly, communication with specialists was more satisfactory. *Adapting to Diabetes:* Parents described isolation in caring for their child's T1DM. Family and friends had minimal understanding of T1DM care. Support groups lessened mothers' isolation, but fathers were less positive about this experience. Parental adaptation was more effective when responsibility for diabetes decision-making was shared. All parents reported never mastering diabetes management. *Negotiating Developmental Transitions:* Normative childhood events were stressful requiring that parents balance concerns to foster child participation.

Conclusions—Pediatric providers can improve diagnostic and treatment experiences for parents of T1DM children by recognizing feelings of isolation and lack of mastery, providing attentive communication, encouraging parental teamwork, and offering ongoing anticipatory guidance.

Keywords

parenting; type 1 diabetes; teamwork; qualitative

Introduction

The incidence of type 1 diabetes (T1DM) during childhood has risen globally (Diamond Project Group, 2006). Although children are most frequently diagnosed during puberty, the highest age specific increase has occurred in young children (Green & Patterson, 2001) with approximately 15–20% of new cases diagnosed in children 5 years of age or younger

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(Dabelea et al., 2007; Roche, Menon, Gill, & Hoey, 2005). Findings of a recent U.S. epidemiologic study demonstrate that 14.2% of new diabetes cases occurred in this age group. Diagnosis may be delayed in young children because they present with non-classic symptoms, such as constipation and enuresis, which may go unrecognized until progression to more serious symptoms or diabetic ketoacidosis (DKA) (Roche et al., 2005). In one retrospective review, 60% of children experiencing delayed or “missed” diabetes diagnosis were <5 years of age (Mallare et al., 2003).

Diabetes presents special challenges to parents of young children due to the child’s limited communicative and cognitive skills, finicky eating, and parental lack of experience and skill. Disease management requires “constant vigilance” (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003) since young children are profoundly dependent on others for diabetes care. Diabetes care tasks are complex requiring administration and adjustment of tiny doses of insulin and monitoring for early warning signs of hypoglycemia when the child is unable to recognize and/or communicate symptoms (Ahern & Grey, 1996). Parenting challenges imposed by diabetes can be far-reaching and, for some, overwhelming. In one study, approximately one third of mothers of newly diagnosed diabetic children reported depressive symptoms (Kovacs et al., 1985) compared to 18% of mothers in a community sample (Kavanaugh et al., 2006). Psychosocial factors play an integral role in diabetes management (Delamater et al., 2001) and positive adaptation to diabetes and its daily demands is critical to parents’ ability to successfully manage diabetes.

Although studies have examined early experiences of mothers (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002) and fathers (Sullivan-Bolyai, Rosenberg, & Bayard, 2006) raising young children with diabetes, research has not explored parents’ ongoing adaptations and experiences to diabetes in children diagnosed early in life, 5 years of age or younger. The purpose of this study was to identify parents’ perceptions of salient psychosocial adaptations in parenting their young children with T1DM from the time of diagnosis through the course of childhood.

Methods

Setting and Sample

Purposive sampling strategies (Rice & Ezzy, 1999) were used to identify participants with a range of parenting experiences (e.g. parenting more than one child with diabetes, a parent with diabetes) relevant to the research purpose. Parents of children diagnosed with T1DM at age 5 years or younger were recruited from a diabetes day camp for children in Suffolk County, New York. Additionally, parents were recruited through word of mouth from a parent who had participated in the study. Parents chose to participate either individually or as a couple. Couples were interviewed separately.

The study protocol was reviewed and approved by the Institutional Review Board of Columbia University Medical Center. Prior to each interview, written informed consent was obtained from study participants. Each participant received \$50 for their participation.

Data Collection

Prior to the interview, parents completed a questionnaire to elicit demographic characteristics and information regarding the child’s diabetes duration and type of insulin therapy. We developed an interview guide consisting of open-ended questions and prompts following review of literature regarding parenting and chronic illness and informed by clinical practice experience in pediatric endocrinology (AS) and clinical psychology (MR) (Table 1). Interviews were conducted by AS in participants’ homes, digitally audio-recorded, transcribed and reviewed to assure accuracy.

Data Analysis

Interview transcripts were coded independently by the authors for identification of initial themes and then checked for inter-rater agreement. Content analysis (Krippendorf, 1980; Neuendorf, 2002) was conducted by marking and categorizing key words and phrases to identify psychosocial themes of relevance to study participants. Themes were reviewed, discussed, and resolved through consensus. Data analysis occurred concurrently with the interview process thereby utilizing constant comparative analysis (Lincoln & Guba, 1985) that allowed for identification of links across themes.

The research team met regularly in face-to-face meetings and by phone for review and discussion of transcript coding, achievement of data saturation, consensus regarding identification and definition of themes, and selection of illustrative excerpts from transcripts. Dependability of the data interpretation was supported by investigator triangulation, a process where more than one investigator analyzes the data (Miles & Huberman, 1994; Russell & Gregory, 2003) through the use of an interdisciplinary team consisting of a nurse researcher and a clinical child psychologist with backgrounds in diabetes treatment and qualitative research. Further triangulation was achieved through review of findings by a research psychologist (KW), clinical child psychologist (EM), and two pediatricians (MM, AO) outside of the research team. Two parent participants also reviewed findings through a qualitative process called member checking that helps assure veracity of findings. Dependability was further ensured through the use of an audit trail to track the decision-making process.

Results

Fourteen parents (3 mothers, 3 fathers, 4 couples) of eleven children (diagnosed at age 3.2 ± 1.7 years, 36% in DKA; diabetes duration 8.0 ± 3.7 years; current age 11.1 ± 3.5 years) (Table 2) were interviewed. One mother had experienced a diabetes diagnosis of two children (ages 14 months and 17 months); another had lived with T1DM for 25 years prior to her child's diagnosis. The majority of children (10 of 11) had transitioned from injection to insulin pump therapy since initial diagnosis. Three pertinent themes were identified: Diagnostic Experiences: Frustrations, fears and doubts, Adapting to Diabetes, and Negotiating Developmental Transitions.

Diagnostic Experiences: Frustrations, fears and doubts

Parents described their experiences preceding, at the time of, and immediately following their child's diagnosis. Fear and doubt pervaded these parents' experiences. Prior to diagnosis, the majority of parents had presented non-specific complaints such as poor sleeping, irritability, or rash to their child's pediatrician but left office encounters feeling that they had not been taken seriously and/or blamed for their lack of parental experience or parenting behaviors.

One father of a girl diagnosed at 11 months of age described his experience of feeling blamed and unheard.

"I remember ...taking her to her pediatrician, because one of the things is she just never slept...she would just wake up screaming and crying. So we had taken her to the doctor... we'd just tell him that there's something the matter and I remember him telling us that it was just us. We were just new parents and that the kid was being manipulative... and he said, 'No, it's just you,' and he kind of just put the blame back on us."

In most cases, mothers were unaccompanied by their partners when first presented with their child's diagnosis. Parent-pediatrician communication varied in terms of perceived empathy, support, and recognition regarding how the parent might feel when receiving the diagnosis. For example, one child diagnosed at 14 months had lost two pounds within a month; following receipt of the diagnosis the mother felt abandoned.

"Then the doctor came in and he said 'okay.' He's a very abrupt man. He came and he pinched (child's) skin and it stood up.... He said, 'Yes, he's very dehydrated.' Then I just said, 'what is wrong with him?' So he came back in and he said, 'there's sugar in his urine. You're going to need to go (to the hospital) now. He's diabetic' and then he walked out of the room. He just left me there with this baby, and I just started to cry."

Although most parents described feeling jarred by the immediacy of hospitalization following diagnosis, they also reported reluctance to leave the hospital and a fearful hesitancy about managing T1DM care of their young child on their own. This mother states: *"I remember the fourth day we were allowed to go home, but I wasn't prepared to even go home and that's how we stayed another day."* Another mother described her fears of giving insulin injections to her child on her own: *"It was like you were killing your own daughter.... I don't think that I'm going to be able to do it."* A father described learning to manage his child's diabetes in the hospital as a *"kind of baptism by fire."*

Following hospital discharge, parents reported how the availability of the diabetes team was an important factor. For example, one mother stated, *"I was on the phone every day with the doctors.... I just got to be more comfortable because that was a great thing that they would answer the phone at any given time."* One parent of a child diagnosed at 4 years of age understood that adjusting to her child's diabetes care was individual and would take time, but she also strongly saw the specialist as a necessary support.

"All the information that they gave us in the hospital was very, very... helpful, extremely helpful. The people were very good. ...diabetes is individual. You have to live with that individual. What works for one is not going to work for another one. So, it's up to the parents that they grow with their child and deal, experience and just have the doctor coach you."

Adapting to Diabetes

All parents described feeling overwhelmed and self-doubting as they adjusted to diabetes care. Some described a fear of not being able to adjust to the newness of diabetes as well as fearing that diabetes had transformed the child they previously knew: *"I felt like my old kid was taken away and now I had this new kid that I didn't know how to take care of. I didn't even know how to go about it."* Another parent stated: *"It's overwhelming in the beginning. You don't know if you can do it. You don't even know your kid that well in that situation. It's like a new experience."*

Many parents talked about sharing diabetes care responsibility with their spouse and how working as a team eased the adjustment process and attenuated the impact of sole responsibility for the child's well being. One mother described her early experiences returning home from the hospital with her 11 month old daughter:

"I was... completely overwhelmed, but my husband... we were a team, so that was huge... We did everything together. We did the checking her together and we... were figuring it out together so that really helped a lot because we didn't feel like we were completely alone."

Another parent of a child diagnosed at 3 years of age commented on the process of informal feedback during daily diabetes decision-making.

“We’ve shared everything right from the beginning.... It’s nice to have someone else to bounce this off of. I’m like...he’s been high here, here, here and here. What do you think? And we figured it out.”

A father of a child diagnosed at 4 years of age described strategies to share responsibility when his work required being away from home.

“We ordered beepers and we would beep. Every time... (she) did a (blood glucose) test we would beep the number...she’d just beep the number and I would call her and we would consult each other.”

Parents often mentioned negotiation in relation to insulin dose.

“We would ask the other what would you give her and then we would compare answers and if we were off a bit we kind of averaged them. So, we had to come up with our own little thing to make sure we were doing it right... god forbid you felt you made a mistake and the kid went low that day...” (parent of a child diagnosed at 23 months)

However, some parents were unable to establish a partnership in care and described the toll this lack of agreement had taken on the marriage. Despite a several year course of diabetes, some parents failed to develop teamwork leading to lack of support and resentment. One mother of a 9 year old girl (diagnosed at 5 years of age) reported:

“...a lot of things I don’t think he does right with this, and I’m sure he thinks I micro-organize the whole thing...He doesn’t get the calls from the nurse. He’s not watching the meter all day with every number that’s coming up and so I think it’s a little more stress free for him.”

Many parents described feeling as though others did not or could not understand diabetes care. They reported that even family members were reluctant to babysit for fear of not knowing how to manage insulin and the child’s reactions to it. A few parents noted that only grandmothers were willing to assist with babysitting enabling parents to trust them to take care of their child. One mother commented on the meaning of her mother’s early involvement in the care of her daughter diagnosed at 11 months of age:

“My mom had made the decision early on that she wanted to take an active role in caring for her... ‘you show me what to do, you go out, you do what you gotta do’. I think...even though it was only temporary, a couple hours or overnight...she understood because she was doing it with me.”

A father of a 9 year old girl (diagnosed at 23 months of age) expressed his long term concern when family members are uncomfortable with participating in diabetes care:

“My mother does the (blood glucose) testing. She won’t do the shots because she’s afraid she’s gonna hurt her. So we always worry ‘who are we gonna leave her with if something were to happen to both of us.’ We still don’t have that answer because I just don’t know who could.”

The majority of mothers described how support group participation allowed them to feel, for the first time, as though others understood them. They were able to talk comfortably and learn from others who had similar experiences. Several mothers described how the support group lessened their feelings of aloneness in parenting their child with diabetes. One saw the support group as a “place where I wasn’t by myself,” and another described how her “experience becomes less isolating.”

However, many fathers did not find the support groups as useful as their wives. They described attending meetings because their wives needed support rather than for their own benefit. They described how it was hard listening to other parents' stories and, at times, it increased their distress. The only mother who stated that the support group was not helpful had diabetes herself. She stated: *"The group is always positive but they'd slip back into things and they'd talk about things that as a kid I went through and it just started bringing it all back for me"*

Each parent was asked about his perception of mastering diabetes care and no parent thought that he/she had achieved mastery. One father of a 17 year old girl (diagnosed at age 30 months) used a "snowflake" metaphor to explain why mastery of diabetes care was difficult.

"I call it (diabetes) the snowflake disease, because not only is it different in every child, it's different every single day minute by minute"

Negotiating Developmental Transitions

The majority of these children's first school experiences occurred after more than a year spent at home living with diabetes. As a result, parents were particularly concerned about how to negotiate with school personnel, staff competence in providing care, entrusting care to another, and their child's acceptance at school.

The mother of two children with diabetes described how her older child's nursery school experience led to distrust and her decision to not enroll her younger child in nursery school:

"I remember one time I called at lunch time, and she (nursery school teacher) said well, "he's been sleeping for two hours now. I raced there and my son's sugar was low. I had to explain to her again."

Parents' kindergarten experiences varied depending on the school's willingness and ability to accommodate the child's needs. For example, one mother described an experience where the school nurse did not seem to understand the unpredictability of diabetes:

"But the thing with diabetes too is ...It's not like you just take your medication. I was explaining that to the (school) nurse. She wants everything written down...I don't know which situations are going to come up. I can't just write down everything that's going to happen. That's impossible."

Another mother's more positive experience supported development of trust about sending her child to kindergarten:

"He went on the (insulin) pump (prior to kindergarten). The (school) nurse knew he went on it in the spring and she came to pump training with us... she wanted to help and she wanted to learn and she was willing to do anything for him...that made me feel much better."

During later school years concerns extended to new areas. One parent described feeling misunderstood by other parents when she accompanied the class on trips in order to allow her child full participation in the school experience. Another expressed the dilemma of disclosing her son's diabetes to coaches during soccer tryouts.

Parents' fears arose when the child faced normative activities of youth. Parents were concerned about whether their child could effectively negotiate these experiences with safety, yet recognized the need to encourage these experiences to promote normal development. For example, sleepovers were seen as anxiety-provoking events because parents were unsure about their child's safety in another's home. This mother described allowing her 9 year old daughter (diagnosed at 5 years of age) to sleep at a friend's home

after the friend's mother promised to do what was expected. She recalled still worrying yet understanding that her daughter needed this normal childhood experience.

"The one friend...said, 'what do I have to do?' ...I said ... If she is low... I'll tell you how we'll play it, but ...she just did it all herself which was good. It was good for (my daughter) because she could be like everybody else."

Parents realized that their child needed to have a sense of independence and self-sufficiency and did not want to compromise the child's sense of being capable. For example, a father described helping his 8 year old daughter (diagnosed at 11 months of age) to be independent, capable, and not disabled by diabetes:

"Let her figure it for herself a little bit and she knows... I just don't want to limit her. I just want to encourage her to be everything that she would be without it. And it's made such a big difference... She is not afraid of doing anything."

However, many parents also expressed concerns and fears about their child's future ability to be independent and eventually leave home. They worried whether their child could manage safely without their assistance and whether a potential loved one would be able or willing to take on the responsibility of diabetes. One father reflected on the future in this way:

"Because last night, my daughter (9½ years old and diagnosed at 5 years of age) registered 38 at about one o'clock in the morning and I say to myself what will happen when she gets older and she doesn't have someone waking her up at 12, 1 o'clock to check her blood? Will she wake up or will she sleep through this? It's almost like when she meets someone when she gets older, I've got to sit this guy down and talk to him...you have a lot of responsibility on your shoulders because you have to look out for my daughter."

Discussion

In this study, parent interviews provided qualitative data regarding parenting young children with diabetes over time. From these discussions, three pertinent themes were identified: Diagnostic Experiences: Frustrations, fears and doubts, Adapting to Diabetes, and Negotiating Developmental Transitions. Of particular significance, no parent reported achieving mastery in caring for his/her child although, on average, eight years had elapsed since diagnosis. Health professionals need to recognize that adjustment to diabetes is an ongoing dynamic process with no discrete endpoint. At different stages new issues arise which require parents and children to revisit and incorporate the demands of diabetes care into new psychosocial contexts.

Initial diagnostic communication was unfortunately not viewed as positive. Prior to diagnosis parents had reported non-specific complaints to their pediatrician but typically felt that their concerns had been minimized or dismissed. Conveying a lifelong diagnosis is one of the most difficult tasks in pediatric primary care. Pediatric providers may not expect to encounter T1DM in young children during an office visit and therefore are unprepared when confronted with the diagnosis. Findings of a large population based study (Rewers et al., 2008) demonstrated that although the prevalence of diabetes is lowest in young children (16.2%), DKA presentation at diagnosis is highest (37.3%), illustrating that earlier more subtle symptoms may be under-recognized or misdiagnosed in this age group (Mallare et al., 2003). Heightened awareness of the changing epidemiology of type 1 diabetes particularly among young children should alert primary care providers to consider the possibility of type 1 diabetes when parents report unusual or persistent non classical symptoms. Improving diagnostic conversations includes strategies such as ensuring that both parents are present,

remaining seated during the conversation, briefly explaining what to expect, and reinforcing the primary care provider's ongoing role as part of the child's care team (Krahn, Hallum, & Kime, 1993). These behaviors may promote open compassionate communication with families needed for positive adaptation to illness, treatment adherence and long term outcome (Levetown, 2008).

Once the diagnosis of diabetes is conveyed, prompt medical attention is needed which, in most cases, includes referral to a diabetes specialist and/or diabetes team. The unexpectedness of diagnosis and need for immediate response provides little opportunity for parents to emotionally prepare for the demands of caring for their newly diagnosed child (Lowe & Lyne, 1999). Although most children in our parent sample were hospitalized at diagnosis, responses of our parent sample are similar to those of newly diagnosed children who received initial management at home (Lowe, Lyne, & Gregory, 2004). Perry and Ireys (2001) examined mothers' perceptions of primary care and subspecialty providers of children with a variety of chronic health conditions. Paradoxically, although mothers placed greater reliance on primary care providers and felt the primary care provider knew their family best, they reported greater satisfaction with care provided by their child's subspecialist. In another study of parents of asthmatic children (Cohen & Wamboldt, 2000), researchers reported similar findings. These results are similar to findings in this study. Parents may be unclear regarding the role of the primary care provider in their child's care following a diagnosis of diabetes. Identifying clear lines of responsibility between the primary care provider and diabetes specialist is important to the establishment of an effective medical home model for children with diabetes (Wegner et al., 2008). Primary care practitioners can assist parents by clarifying domains of responsibility and identifying aspects of care common to both primary and specialty care providers thereby promoting effective navigation of care by these families.

Parents described feeling very alone in managing their young child's diabetes; lack of support and understanding by family and friends contributed to these feelings of isolation. Although support groups lessened feelings of aloneness, particularly for mothers, they were not seen as favorably by most of the fathers in our study. Further research is needed on developing ways to assist parents with their feelings of isolation and needs for social support in families and their communities. Options for social support should be routinely offered to parents. The American Diabetes Association "Family Link" Website (<http://www.diabetes.org/family-link/support-for-your-family.jsp>) offers a variety of resources to families with diabetes. Parents have the option to be matched with a trained parent mentor to share personal experiences and offer information and support. In addition, the site provides access to message boards and information regarding care of the child with diabetes at school.

When parents were able to collaborate on their child's treatment decisions, perceptions of effective treatment occurred. The importance of establishing partnerships in care (Sullivan-Bolyai, Rosenberg, & Bayard, 2006) has been previously reported in a sample of fathers of young children with diabetes. Our study both confirms these earlier findings in a different sample of fathers and expands this finding by describing the importance of partnership from the perspective of mothers. In this study, teamwork fostered shared responsibility and collaboration in daily decision-making, notably insulin dosage and adjustment, and may be important in fostering family adaptation, resilience, and mastery. Pediatric clinicians have a unique opportunity to promote parent collaboration in the care of young children with diabetes. Meeting with both parents as soon as feasible sends a message that involvement in care is a shared responsibility. Further research is needed to explore how parental teamwork influences diabetes management and family functioning.

School entry represents the first physical and emotional separation from parents (Garrison & McQuiston, 1989) and requires parents to trust that school personnel will be attentive and competent to ensure the child's optimal health. School becomes the place where children learn about achievement and social contacts (Achenbach, 1982). In this study, one mother was less concerned about school when the school nurse volunteered to learn about the insulin pump. However, other parents were concerned when school personnel did not understand the nature of diabetes management and over-relied on parents as care coordinators. Assistance to parents with school concerns may involve helping them identify resource people within the school system in order to institute a plan for diabetes management at school ("Sample section 504 plan & diabetes medical management plan for a student with diabetes,") or recommending diabetes education resources for school personnel.

Most parents in this study understood that their child needed to develop autonomy and independence despite their fears and concerns about sending the child into the world. They recognized that over-protectiveness was not in their child's best interest but struggled to find the right balance. Anticipatory guidance during routine office visits can help parents realize the need for appropriate parent child boundaries as well as promote the child's engaging in developmentally appropriate independent activities. In a recent survey of North Carolina pediatricians and endocrinologists (Wegner et al., 2008), the majority of respondents concurred that routine anticipatory guidance of children with T1DM was a responsibility of primary care providers; however, responsibility for issues such as transition to adult care and communication with school personnel was less clear.

Both mothers and fathers stated that they did not want their child to feel that diabetes interfered with his/her normal development, but they also understood that there is a realistic emotional cost of diabetes and unique challenges to child-rearing. Parents also expressed concerns about future transition to independent living.

Adolescence and transition to independent living can be difficult times for families with diabetes (Weissberg-Benchell, Wolpert, & Anderson, 2007). Several parents in our study mentioned concerns about this developmental transition, particularly with regard to nocturnal hypoglycemia. Interestingly, one study found that 68% of diabetes-related deaths in young adults were associated with hypoglycemia or ketoacidosis (Laing et al., 1999). Therefore, these concerns are neither unfounded nor mere reactions of over-protective parents. How can health professionals best assist parents of children with T1DM navigate the transition to independent living? One suggestion is to help parents of chronically ill children develop a "life (not illness) plan" for the future (Olsen & Swigonski, 2004). Ongoing conversations about future independence provide opportunities to assess developmentally appropriate delegation of responsibility and support adolescents in learning to problem solve diabetes management issues effectively while still under parental guidance and tutelage. In addition, discussion of promising technological devices such as the continuous glucose monitor may alleviate parents' fears of hypoglycemia (Block & Buckingham, 2008) and holds promise to assist with transitions to independence.

This was an exploratory study whose findings must be considered preliminary. The limitations of this study included a sample of primarily white, college educated parents and, thus, limit generalizability of findings. Data were retrospective in nature rather than throughout the duration of diabetes. However, the research question required reflection of parenting experiences over time and provides insight regarding primary care strategies to support parenting of these young children with diabetes. What remains unclear is whether the experiences described by these parents are unique to parents of children diagnosed at a young age or are similar to those of parents of children with type 1 diabetes diagnosed after

age 5 years. Further research is needed to explore whether age at diagnosis affects ongoing parenting experiences and issues of concern over time.

During office encounters, health professionals can provide invaluable assistance to families of young children with T1DM. Providers' skills to facilitate communication during difficult conversations can be enhanced (Browning, Meyer, Truog, & Solomon, 2007; Krahn et al., 1993; Meyer et al., 2009). Parents need help with feeling less isolated and more competent about their abilities to manage their child's T1DM care. Therefore, primary care practitioners have an ongoing opportunity to assist parents in the demanding care of young children with diabetes by listening empathically, promoting parent collaboration as well as providing anticipatory guidance through the child's developmental and diabetes trajectory.

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Table 1

Interview questions

-
- 1 What was it like for you when you found out that your child had diabetes?
Describe your early learning experiences and how they occurred.
How did you feel about your ability to do all of this when ___ was discharged from the hospital?
What things were most difficult to learn?
 - 2 When you first went home from the hospital, what was it like to take care of ___ ?
How did you feel about managing all of this?
Was it difficult finding enough time to meet the needs of other family members?
 - 3 Were you employed outside the home and how did you deal with that when ___ came home from the hospital?
 - 4 Tell me about the involvement of your family, friends, and co-workers.
How involved do you think family members should be?
 - 5 Who were the people you could turn to for support or guidance?
What types of things did you discuss?
 - 6 In which ways has diabetes affected your family life?
 - 7 How long did it take for you to feel that you had mastered taking care of ___'s diabetes?
Describe examples of how you knew this had occurred.
 - 8 Looking back over your own experience, what things would have been helpful to you in making the adjustment to parenting a child with diabetes?
-

Table 2

Demographic characteristics of interview participants and their children

	N	%
Parents N=14		
Gender Female	7	50
Current Age (years) Mean±SD		41.7±5.0
Married, Living with Partner	14	100
Race/Ethnicity		
Non Hispanic White	13	93
Hispanic	1	7
Education		
Some college	4	29
College graduate or greater	10	71
Current Employment		
Fathers		
Full time	7	100
Mothers		
Full time	2	29
Part time	2	29
Not employed outside home	3	42
Children N=11		
Gender (Female)	7	64
Hospitalized at diagnosis	10	91
Age at diagnosis (years) Mean±SD		3.2±1.7
Current age (years) Mean±SD		11.1±3.5
Diabetes duration (years) Mean±SD		8.0±3.7