

CONSTRUCTING A GROUNDED THEORY OF INFLUENCES ON PATERNAL
INVOLVEMENT IN THE TREATMENT AND CARE OF CHILDREN WITH
TYPE-1 DIABETES

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INVOLVEMENT IN THE TREATMENT AND CARE OF
CHILDREN WITH TYPE-1 DIABETES

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Abstract

This dissertation was a grounded theory study of paternal involvement in the treatment and care of children with type-1 diabetes. The ultimate goal of this study was to generate a theoretical model of the influences on paternal involvement in the treatment and care of children with type-1 diabetes. The primary research questions addressed in this study were, “How are fathers involved in the treatment and care of children with type-1 diabetes?”, and “What influences paternal involvement in the treatment and care of children with type-1 diabetes?” I interviewed 15 fathers of children with type-1 diabetes who were attending physician appointments at two regional hospitals in the Midwestern United States. Fathers described several family processes (e.g., navigating the emotional waters, balancing work and family demands, building trust within the parental treatment team, and encouraging child responsibility for treatment) that influenced how they shared the responsibility for the care and treatment of the children with mothers. Fathers also were categorized into several types of involvement (e.g., not involved, helper, equal partner, treatment monitor, primary caregiver) based on their reports of how they shared the responsibility for treatment.

Chapter 1

Introduction and Literature Review

Purpose and Rationale of the Study

The main purpose of this study was to generate a theoretical model of the perceived influences on paternal involvement in the treatment and care of children with type-1 diabetes (T1D). The primary research questions addressed in this study were, “How are fathers involved in the treatment and caregiving of children with T1D?” and “What influences paternal involvement in the treatment and caregiving of children with T1D?” Fathers were asked about their experiences in caregiving and treatment for a child with T1D, and they were asked what helped or hindered their involvement. A secondary purpose of this study was to determine how fathers wanted to be involved in their children’s treatment.

The importance of studying paternal involvement in the treatment of type-1 diabetes. Much of the research on family caregiving of children with T1D has focused on mothers because they provide most of the in-home treatment and other care of children with diabetes (Palmer et al., 2009; Seiffge-Krenke, 2002). Mothers of children with T1D experience high levels of stress connected to their involvement in treatment and caregiving, and there is evidence that mothers’ stress is related to the amount of help they receive from others, particularly from fathers (Gavin & Wysocki, 2006; Wysocki & Gavin, 2004; Wysocki & Gavin, 2006). When fathers are more involved in treatment of children with diabetes and other illnesses, mothers are less stressed and have greater well-being (Gavin & Wysocki, 2006).

Not only do mothers benefit from fathers' involvement in treatment, but children benefit as well. Researchers have found that paternal involvement in treatment is positively associated with maintenance of children's treatment regimens (Wysocki & Gavin, 2006), and fathers' monitoring of treatment is positively associated with better metabolic control through higher levels of children's adherence to treatment (Horton, Berg, Butner, & Wiebe, 2009).

Because of the positive associations between paternal involvement in treatment and children's and mothers' well-being, it is important for researchers to continue to explore paternal involvement in the treatment of children with T1D. In particular, researchers should focus on fathers' perceptions of what helps and hinders their involvement in the treatment of their children with diabetes. Such information could be used to inform interventions aimed at encouraging paternal involvement in treatment, which could improve children's health outcomes.

Childhood Diabetes

T1D is characterized by a deficiency of the pancreas in which pancreatic cells are unable to produce the insulin the body needs to properly metabolize sugars (American Diabetes Association, 2013). Because the pancreas cannot produce insulin, people with T1D are entirely dependent on insulin injections for metabolic control, which is why T1D is also called insulin-dependent diabetes mellitus. T1D is one of the most common childhood chronic illnesses. In 2007, there were 17.9 million diagnosed cases of diabetes, and approximately 10% of those cases were type-1 (juvenile-onset) diabetes (Centers for Disease Control and Prevention, 2007).

Demands on parents of children with T1D. Daily home treatment of T1D is intense, requiring meal planning, exercise, glucose testing, and insulin injection, all with the goal of maintaining metabolic control (i.e., healthy blood glucose readings; Butner et al., 2009). The demands on parents of children with T1D are great. Parents are faced with the challenges of learning about T1D and how to deliver proper treatment and care, and then managing and monitoring their children's performance of treatment tasks. Parents of children with T1D not only have to engage in daily childrearing activities that are typical of parents of well children, but some childrearing activities must be modified to account for their children's illness (e.g., finding child care providers who are qualified to care for children with T1D; Beveridge, Berg, Weibe, & Palmer, 2006; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002).

Treatment and caregiving tasks. The treatment tasks in which parents engage with their children depend on factors such as child age and treatment type (e.g., multiple daily injections, insulin pump). Parents of younger children with diabetes tend to be much more involved in treatment tasks than are parents of adolescents (Dashiff, Vance, Abdullatif, & Wallander, 2008; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). Younger children are not considered by physicians or their parents to be capable of reliable blood-glucose monitoring and insulin injections; therefore, parents tend to be primarily responsible for these tasks. On the other hand, adolescents are often given more responsibility for blood glucose monitoring and insulin injections while parents decrease their involvement (Dashiff et al., 2008; Urbach, LaFranchi, Lambert, Lapidus, Daneman, & Becker, 2005); however, metabolic control and treatment management typically worsen during adolescence, which is distressing to parents

(Streisand, Swift, Wickmark, Chen, & Holmes, 2005). The reduction in consistency of metabolic control and treatment management can also contribute to future diabetes complications, such as coronary artery and renal disease, vision deficits, diabetic ketoacidosis, and neuropathies (Silverstein et al., 2005). The dangers associated with adolescents' poor metabolic control highlight the need for parents to continue closely monitoring their adolescents' treatment management, although their direct involvement in treatment tasks may be reduced.

The treatment tasks in which parents and children engage also depend on the type of treatment prescribed by physicians. Two basic types of treatment for T1D exist: Multiple daily injections (MDI), and insulin pumps (Sullivan-Bolyai, Knafl, Tamborlane, & Grey, 2004). When using MDI, parents and children must constantly monitor blood glucose readings manually (i.e., finger prick), track exercise and carbohydrate intake, and manage blood glucose levels with measured injections via syringe of combinations of short-and long-acting insulin. Insulin injections typically happen before or after meals.

Insulin pumps, on the other hand, mimic the functioning of a working pancreas by slowly injecting small amounts of insulin over the course of a day (i.e., physician prescribed), with bolus doses of insulin injected around mealtimes (Sullivan-Bolyai et al., 2004). There are two types of insulin pumps: Those that include a glucose monitor and those that do not. With insulin pumps that include a glucose monitor, a small transmitter is placed at the injection site that sends a signal about blood glucose levels to the pump. The monitor does not replace the finger prick method of glucose monitoring, though; it is still used to confirm the accuracy of the readings from the pump's glucose monitor.

The primary difference between MDI and insulin pumps that is important to parental involvement is the method of blood glucose monitoring and injections needed. With MDI, blood glucose monitoring and injection are accomplished manually, but they are automatic with the use of some insulin pumps. On the other hand, insulin pumps can be labor-intensive because of the need to change injection sites every few days and confirm blood glucose readings using the finger prick method. Mothers are likely to be more consistently involved with MDI than are fathers (Sullivan-Bolyai et al., 2002; 2003). On the other hand, there is evidence from one study that fathers may be more involved with treatment management when an insulin pump is used compared to MDI (Sullivan-Bolyai et al., 2004). Several mothers in that study perceived that fathers were more involved because they were fascinated by the technology of the insulin pump.

Parents of children with T1D not only have to manage at-home treatment for T1D, but they, of course, must engage in typical parenting activities. The study of how parents raise children with T1D is somewhat new, but the few studies performed have revealed several differences between parenting healthy children and parenting children with T1D. For instance, mothers of children with T1D face challenges in finding suitable child care providers who are qualified to care for a child with T1D (Sullivan-Bolyai et al., 2002). One of the primary challenges mothers of children with T1D face is allowing their child to become more responsible for their own treatment management in developmentally appropriate ways (Dashiff et al., 2008; Sullivan-Bolyai et al., 2002; 2003). Encouraging children's autonomy development is a challenge also faced by parents of healthy children, but when children have chronic illnesses such as T1D that require intensive at-home treatment, autonomy development presents challenges because

of parents' anxiety over the dangers attached to poor treatment management, and parents' perceptions of their children's vulnerability (Mullins et al., 2007).

Younger children with T1D, as they experience developmentally appropriate yearnings toward autonomy (autonomy vs. shame and doubt; Erikson, 1968), may attempt to gain control by resisting insulin injection and glucose monitoring (i.e., which can be painful) on the one hand, while on the other hand attempting to help by giving themselves injections (Sullivan-Bolyai et al., 2003). As children with T1D move through adolescence, they typically take on more responsibility for daily treatment tasks. For adolescents to become more skillful at managing their own treatment, and eventually to do so entirely without their parents' help, it is necessary for them to become more autonomous (Dashiff et al., 2008).

In addition to the challenges of facilitating appropriate autonomy development, parents of children with T1D also struggle with the complications that T1D brings to discipline, especially for younger children. Because younger children are less skilled at verbalizing how they feel and monitoring their own physiological cues, mothers of young children with T1D describe engaging in "constant vigilance" with regard to their children's behavioral cues (e.g., irritability, severe fatigue; Sullivan-Bolyai et al., 2002; 2003, p. 24), which may provide a signal that the child is hyper- or hypoglycemic. This "constant vigilance" also may help parents know when their children's irritability or poor behavior may actually be due to a diabetic reaction rather than normal defiance. Parents may modify their discipline strategies when they know their children are hyper- or hypoglycemic.

Most of the literature on how parents raise children with T1D has focused on mothers; only one study was found that investigated fathers' parenting behaviors. Seiffge-Krenke (2002) found that fathers who were given a non-illness specific problem-solving task to complete with their adolescent children with T1D were less communicative and showed lower initiative in solving the task than were fathers of healthy children.

Knowledge about diabetes. Another significant challenge parents face is learning about treatment regimens and about the short- and long-term complications and consequences of diabetes for their children (Buckloh et al., 2008; Butler et al., 2008; Collier, Pattison, Watson, & Sheard, 2001). Parents' knowledge of treatment must extend beyond skills associated with basic glucose monitoring and insulin injection. Parents must also be aware of the impact of diet (i.e., particularly carbohydrate intake) and exercise on children's glucose levels, and plan for that impact in their children's insulin doses. Mistakes in planning, monitoring of glucose levels, and insulin doses can have detrimental effects on children's health, the possibility of which frightens many mothers and fathers (Buckloh et al., 2008). When parents understand more about treatment, their children tend to maintain better metabolic control (Butler et al., 2008).

Some researchers have tested parents' treatment knowledge and found differences between mothers and fathers (Hackett, Court, Matthews, McCowen, & Parkin, 1989; Janisse, Naar-King, & Ellis, 2010). Although mothers and fathers displayed adequate knowledge and health literacy in both studies, upon follow-up seven months after the education program they implemented, Hackett et al. (1989) found that fathers did not retain as much information as did mothers. It is possible that mothers retained more

information because they were more involved in treatment than were fathers, which allowed them to practice skills they had learned.

Parents of children with diabetes also desire knowledge about the short- and long-term complications of T1D (Buckloh et al., 2008). Short-term complications include hyperglycemia, hypoglycemia, and ketoacidosis, which can be fatal (American Diabetes Association, 2013). Long-term complications include vision problems, neuropathies, coronary artery disease, and renal failure (American Diabetes Association, 2013). It has been found that parents desire more information about these issues to prepare themselves for possible health problems their children may experience in the future, and so that they can educate their children about the disease when their children are ready for the information, and be emotionally supportive of their children when complications arise (Buckloh et al., 2008). Encouraging fathers to provide emotional support and education to their children with T1D could be a way to encourage fathers' overall involvement in treatment and caregiving.

Parental stress and coping. Mothers of children with T1D experience heightened levels of stress because of the difficulties associated with treatment management, and worries over diabetes complications (e.g., hypoglycemia; Sullivan-Bolyai, 2002, 2003). In addition, there is evidence that parental stress is attached to the initial diagnosis of diabetes itself (Landolt et al., 2002). Parents of children newly diagnosed with T1D have displayed symptoms of post-traumatic stress disorder soon after the diagnosis. Mothers also tend to experience increasing stress levels after the first year following diagnosis (Kovacs et al., 1990), although their knowledge and skills in treatment increase over time.

Parents' stress levels associated with their children's diabetes are likely related to their coping strategies. Researchers have found some differences between mothers' and fathers' coping strategies in response to stress over their children's T1D (Azar & Solomon, 2001; Dashiff, 1993; Smith, Dickerson, Saylor, & Jones, 1989). Mothers used coping strategies aimed at increased treatment management (e.g., planful problem solving) while fathers engaged in distancing strategies. Smith et al. (1989) found that fathers' distanced themselves because of difficulties becoming involved in daily care, which they attributed to mothers' higher levels of involvement in care. There are also some similarities between mothers' and fathers' coping strategies. Both mothers and fathers are likely to use adaptive coping mechanisms such as social support and positive reappraisal (reframing; Azar & Solomon, 2001; Seiffge-Krenke, 2002). In fact, fathers of diabetes children were more likely to use reframing than were fathers of healthy children (Seiffge-Krenke, 2002).

The issue of stress and coping may be particularly useful for understanding father involvement in treatment and care of children with T1D. Fathers' lower involvement compared to mothers may be due, in part, to their use of distancing as a coping strategy in response to stress. Practitioners attempting to encourage paternal involvement in treatment and care may do so more effectively by promoting the use of more adaptive coping strategies (e.g., reframing and social support).

Predictors of paternal involvement in the treatment and care of chronically ill children. Although there has been little research on predictors of father involvement in the treatment and care of children with T1D, research on parents of children with other chronic illnesses may provide clues about such predictors. Gayer and Ganong (2006)

found that mothers perceived that married fathers of children with cystic fibrosis were more involved with care than were divorced fathers and stepfathers. The lower level of involvement among divorced fathers is particularly troubling because they are often solely responsible for care when the children are in their households. If these fathers are poorly educated on children's diseases or generally unaware of treatment protocols, their children may be less likely to receive adequate care when they are with the fathers. Communication and cooperation between mothers and fathers about at-home treatment regimens is complicated in divorced and separated families, but could be crucial to the maintenance of treatment for children with chronic illnesses.

Some attention has also been given to connections between paternal involvement in care and illness characteristics. According to McNeill's (2004) grounded theory study, fathers of children with juvenile rheumatoid arthritis (JRA) responded to their children's pain with simultaneous feelings of helplessness and protectiveness. Although fathers knew there was little they could do to reduce or eliminate their children's pain, they still increased their engagement in care activities aimed at doing so (e.g., providing ice or heat packs, massages). Fathers of children with T1D also may be likely to feel helpless or protective of children during hypo- or hyperglycemic episodes, which may prompt changes in their involvement.

“New fatherhood” and 21st century expectations for father involvement.

Since the 1970's, one of the predominant perspectives on the role of fathers has been that of active fathering. Fathers are expected to take a more active role in the daily care of children than in previous eras, in which fathers primarily took on the roles of breadwinning and sex role modeling (Lamb, 2000). As societal perspectives on

fatherhood have shifted, so have the study of fatherhood. One of the seminal developments in conceptualizing fatherhood was Lamb and colleagues (1985; 1987) proposal that father involvement had three components: *Engagement* (i.e., direct interaction with children; playing, caretaking, leisure, nurturance), *accessibility* (i.e., activities that do not include direct interaction, but fathers are still physically accessible to their children; emotional availability), and *responsibility* (i.e., ensuring care for children, arranging resources, breadwinning). They proposed that fatherhood should not be measured in terms of amount of time spent in various parenting activities, but by the range of “development-enhancing” activities in which fathers engage. The strengths of this conceptualization of fatherhood are that it is inclusive of multiple aspects of fatherhood, and allows for a focus on both quality and quantity of interaction between fathers and their children.

Pleck (2010) has since re-conceptualized father involvement to include *warmth*, *control*, *process responsibility* (i.e., making sure the child is taken care of) and *indirect care* (i.e., arranging for resources to be available). This new conceptualization is relevant to paternal involvement in children’s chronic illness treatments.

Lamb et al. (1985) proposed a four-factor model of the sources of influence on father involvement in parenting. This model could provide clues about sources of influence on fathers’ treatment involvement. The model included: 1) motivation, 2) skills and self-confidence, 3) social supports, and 4) institutional barriers. The motivation factor included such conditions as children’s gender, gender role beliefs, and parenting role models. The skills and self-confidence factor referred to father’s real and perceived parenting abilities. The social supports factor included external familial and community

supports, but Pleck and Masciadrelli (2004) proposed that the most important social support comes from their children's mothers. Finally, the institutional barriers factor most prominently included fathers' work environments.

In summary, research has revealed some factors that could be connected to paternal involvement in treatment (e.g., children's involvement in treatment, emotions, knowledge of treatment, marital status), but the associations between these factors and how fathers are involved in treatment remain unclear. A grounded theory investigation could provide new information about these associations, in addition to information about the interactions between factors. Knowing what fathers think about conditions and persons that either help or hinder their involvement in treatment also could assist practitioners to know when and how to encourage more paternal involvement in care.

Chapter Two

Methods

Rationale for a Grounded Theory Approach

Grounded theory was the method of choice in this investigation because of the wide gaps in what is known about contextual influences on paternal involvement in the treatment and care of children with chronic illnesses. Where such gaps in scholarly knowledge exist, an approach that generates new and unique concepts and explanations about the phenomenon directly from the data may be extremely useful (Birks & Mills, 2011). A grounded theory exploration of paternal involvement in care of chronically ill children would produce concepts that describe contextual factors that influence paternal involvement in care, and an integrated theory, grounded in data, which provides possible explanations of how these factors help or hinder paternal involvement in care.

In addition, grounded theory methods assume that the generation of outcomes occurs within the context of a complex environment. Grounded theorists conceptualize this context as the conditional/consequential matrix (Corbin & Strauss, 2008). The conditional/consequential matrix provides a framework for researchers to relate structure to process, and consists of several “ideas” regarding this interplay. One idea is that conditions and consequences “do not exist in a vacuum” (Corbin & Strauss, 2008, p.91), meaning that the circumstances that trigger one’s actions and expressions of emotions, and the consequences that follow one’s actions and emotional responses, are part of a recursive process. They are often dependent on one another.

Another idea is that “the distinction between micro and macro is... artificial” (Corbin & Strauss, 2008; p. 91), which means that conditions of actions are often a

combination of micro conditions (e.g., family, community) and macro conditions (e.g., historical, political). Grounded theorists make attempts to track the influence of the interplay of micro and macro conditions on the processes that produce outcomes. A grounded theory exploration of paternal involvement should be sensitive to interactions among sources of influence on paternal involvement, which could contribute to the further development of current theories on sources of influence that consider each source separately (Pleck and Masciadrelli, 2004).

Finally, grounded theorists assume that individual research participants are not always aware of the range of micro and macro conditions at play in their lives, nor are they aware of the interplay of those conditions (Corbin & Strauss, 2008). Therefore, grounded theory researchers must listen to many people to have an opportunity to comprehensively understand human experience related to a certain phenomenon, and researchers should be attuned to environmental conditions that appear in their participants' responses so that they might be prepared to ask for clarification from their participants.

Sample Characteristics, Recruitment, and Procedures

The participants in this study were biological fathers and stepfathers (n=15) of children ages 3-17 with type-1 diabetes. Seven of the children were male, and eight were female. The children were diagnosed with type-1 diabetes between the ages of 2 and 15. The length of time between diagnosis and the time of the interview ranged between 3 months and 8 years.

The fathers were between the ages 26 and 61, with an average age of 44. All were employed full-time, mostly in "white collar" jobs (e.g., management, sales, business

owners), but three were employed in “blue collar” jobs (e.g., construction, police officer). Fourteen of the fathers were White and one was Black.

Descriptions of the fathers. The following section contains a brief description of the fathers in the study.

Father #1 was a White male; he and his spouse were in their mid-40’s. This was a first marriage. Their daughter was 15 years old at the time of the interview, and was about 10 years old when she was diagnosed with T1D. She had three siblings. The father was employed full-time in two “blue collar” jobs. His spouse was a stay-at-home mother. At the time of the interview, his daughter was almost fully responsible for her own treatment and his primary role was that of a treatment monitor.

Father #2 was a White male; he and his spouse were in their mid- to late-40’s. They were both in their first marriage. Their son was 13 years old at the time of the interview, and was 10 years old when diagnosed with T1D. They had one other son. The father was employed full-time in “blue collar” work, and his spouse worked part-time out of their home. This father described his division of treatment labor as equal with his wife, but also described himself as being burdened with treatment because his spouse did not fully understand some aspects of treatment, and his child was less responsible for treatment than he would like.

Father #3 was a White male in his mid-50’s whose spouse was in her mid-40’s. Both were in their first marriage. Their daughter was 15 years old at the time of the interview, and had just been diagnosed less than 6 months before the interview. She had three siblings. The father ran his own business and his spouse was employed full-time and traveled a lot for her work. Although this father was home without his spouse many

days during the week, and sometimes for weeks at a time, he considered treatment to be shared equally because his spouse took over treatment when she returned home, and he frequently called her for help in calculating insulin dosages. Because his daughter had just been diagnosed a few months before the interview, she had not had time to become fully responsible for treatment, despite her age.

Father #4 was a White male in his late 40's, with a spouse who was in her early 50's. Their child was 16 years old at the time of the interview, and was diagnosed with T1D at age eight. She had one sibling. The father ran his own business with his spouse. This father was also a type-1 diabetic. He described himself as highly involved in treatment when his child was first diagnosed, and maybe even a little more involved than his spouse in treatment because she did not like giving their daughter shots. However, soon after diagnosis, their daughter quickly became more responsible for her own treatment, and his primary role became that of a treatment monitor.

Father #5 was a White male in his early 40's whose spouse was in her mid-40's. Their daughter was 17 years old at the time of the interview, but was 11 years old when she was diagnosed. She had no siblings. The father was employed full-time in sales and as a consultant. His spouse was a stay-at-home mom. He described himself as not involved in day-to-day treatment and that his spouse was the primary caregiver. He saw his main role as that of a financial provider and decision-maker about treatment.

Father #6 was a White male; he and his spouse were in their mid-30's. Their daughter was 7 years old at the time of the interview, and was 2 years old at the time of diagnosis. She had one younger sibling. The father was employed full-time, and his spouse decided to stay at home after their child was diagnosed. The father initially

described the division of labor with treatment as being equal, but as he continued to describe the family's routine, it became apparent that the mother was the primary caregiver and the father's role was more as a helper to her, although he was somewhat independent in his involvement in treatment.

Father #7 was a White male in his early 40's who was in the process of divorcing his spouse. His daughter was 12 years old at the time of the interview, and was 6 years old when diagnosed. She had one older full sibling, and several half-siblings from one of the father's previous relationships. The father was employed full-time, and his ex-spouse was employed part-time. The father described himself as the primary caregiver, stating that he didn't trust his ex-spouse to be able to take care of his daughter, and that she frequently had to call him for help.

Father #8 was a White male in his mid-40's whose spouse was in her late 30's. This was their first marriage. Their son was 6 years old at the time of the interview, and was 4 years old when diagnosed with T1D. He had one younger sibling. The father worked full-time in management while his spouse was a stay-at-home mom. The father described himself as a helper to the mother, who was a primary caregiver.

Father #9 was a White male; he and his spouse were in their mid-20's. This was their first marriage. Their son was three years old at the time of the interview, and was diagnosed at the age of two. He had one younger sibling. The father was employed full-time in management, and his spouse was a stay-at-home mother who worked part-time before her child's diagnosis. This father changed jobs after his son was diagnosed to increase his work flexibility. The father described an equal division of labor in treatment across the interview.

Father #10 was a White male in his early 40's whose child's mother was in her mid-30's. They were not married to one another, but both have married other people since their separation. Their son was 13 years old at the time of the interview, and was diagnosed less than 6 months before the interview. The father owned his own business, and his wife, child's mother, and her husband were all employed full-time as well. Their son was fully responsible for his own treatment, and the father described his primary job as that of a treatment monitor.

Father #11 was a White male; he and his spouse were in their mid-40's. They were both in their first marriage. Their daughter was 13 years old at the time of the interview, and was 5 years old when she was diagnosed with T1D. The father was employed full-time in upper management, and the mother was employed full-time as a nurse. Although their daughter had taken over some of the responsibility for her own treatment, the father described the division of labor in treatment as equal from the time of his daughter's diagnosis to present day. This father frequently left work to take care of his daughter when needed, and he often took phone calls from her while at work.

Father #12 was a White male in his early 40's whose spouse was in her late 30's. He was not the biological father to his child. His spouse was never married to their child's biological father, and the biological father was not involved in the child's life. Their son was nine years old, and was diagnosed when he was seven years old. The father was employed full time in a "blue collar" job, and his spouse was employed full-time as a clerk. His spouse was the primary caregiver and the father was minimally involved in treatment, mainly in relaying messages between the mother and son about how much of an insulin bolus to dial into the pump.

Father #13 was a White male; he and his spouse were in their early to mid-40's. This was their first marriage. Their son was 14 years old at the time of the interview, and was diagnosed at the age of 6. He had two younger siblings. Both parents were employed full-time in similar jobs, and worked opposite shifts. The father described an equal division of labor with treatment that was necessitated by the opposing shift work.

Father #14 was a Black male; he and his spouse were in their mid-40's. This was their first marriage. Their daughter was 17 at the time of the interview, and was 13 years old at the time of the diagnosis. She was an only child. Both the father and mother were employed at the time of the diagnosis, but she stopped working outside the home soon after the diagnosis. The father worked full-time. The daughter was responsible for her own treatment, even to the point of going into the doctor's office for appointments by herself. The father's main role was that of a treatment monitor.

Father #15 was a White male in his early 60's whose spouse was in her mid-30's. Both of them were repartnered (his spouse was never married to the biological father of her children), and she had children from a previous relationship, in addition to two they conceived in their relationship. The child with diabetes was a stepson to this father. He was 11 years old at the time of the interview, and was 7 years old at the time of diagnosis. This father owned several businesses, and his wife worked part-time periodically in them. He described the division of treatment labor as equal throughout the interview.

Recruitment. Fathers were recruited through two pediatric endocrinology clinics in the Midwestern United States. Per my agreement with the staff of the endocrinology clinics, I went to the clinics to recruit fathers directly. The fathers were recruited either by speaking with them directly during their children's appointments, or by calling them

on the telephone after receiving contact information from them or their children's mothers. During this contact, fathers were provided with packets that contained recruitment letters addressed to fathers (Appendix A), one addressed to mothers if the fathers were not at the appointments (Appendix B), and an informed consent document (Appendix C). Because it was usually mothers who brought their children for appointments (Ahmann, 2006), I relied frequently on mothers to bring the recruitment packets to the child's father or stepfather. The recruitment letters and informed consent documents included an email address and telephone number for fathers to contact me if they were interested in participating in the study. Six interviews were conducted face-to-face and on-site; nine interviews were completed via telephone.

Only a few inclusion criteria were applied: Children's ages, language spoken by the father, and type-I diabetes. Fathers and stepfathers of children age 3-17 were chosen as the base participant pool because including a broad age range of children allowed me to gain an understanding of how the ages of children may inform paternal involvement in care.

In addition, only English-speaking fathers were included. Only one father was excluded due to this criterion. Although including non-English speakers could have helped provide insight into cultural influences on paternal involvement, it was deemed necessary to enforce this inclusion criterion because of the degree of self-disclosure and complexity involved in the interview process. Unnecessary frustration may have arisen for both the fathers and the researcher if translation were necessary, in addition to data collection problems.

Data generation. A number of different methods were employed in generating data. The majority of the data was obtained through interviews, with additional data generated through memo writing. Using multiple sources of data provided a breadth of information. These data were constantly compared and analyzed, which allowed me to explore and clarify the emerging concepts and themes.

Interviews. The primary data collection method was interviews. Initially, a general outline of questions guided interviews (Appendix D), but this outline changed over the course of the study in response to the concepts analyzed from earlier interviews. All interviews occurred either face-to face or via telephone, and were recorded using a digital voice recorder. Although face-to-face interviews were preferable because of the non-verbal data that could be collected in addition to verbal responses, telephone interviews were necessary because the patient pool from the diabetes clinics was widespread geographically. Fathers were provided with a choice of setting for the interviews.

The initial interviews lasted from 35 minutes to 75 minutes. I began by creating a genogram, a graphical representation of a family's composition (McGoldrick, Gerson, & Shellenberger, 1999). Genograms in qualitative research may be a useful tool for gathering demographic and descriptive data while building rapport with participants. In this study, the genograms also provided a way of tracking who was involved in children's treatment and which family relationships were important to paternal involvement in treatment. The genogram included maps of the immediate family composition, ages and sexes of family members, and illness history in the family. I also included a timeline of events that occurred surrounding the diagnosis of the children's illness (e.g., paternal

involvement before diagnosis, parents' responses to the diagnosis, who brought the children to physician appointments, who learned first how to test blood glucose and provide insulin injections).

After the genogram, I asked the basic questions presented in Appendix D (e.g., "Tell me about your experiences in caring for their child with type-I diabetes?", and "What do you think helps or hinders your involvement in treatment?"). When fathers had difficulty answering general questions about what helped or hindered their involvement, I asked them supplemental questions about work and their relationships with the children's mothers. These questions were based on sensitizing concepts from the literature on father involvement and parents of children with T1D. Sensitizing concepts are derived from pre-existing theory or other empirical sources, and they often form the basis for research problems (Charmaz, 2003).

As the interviews progressed, the questions I asked changed. For instance, my advisor and I realized that I was setting up an arbitrary beginning for the fathers' stories by making the first questions I asked after the genogram about the fathers' experiences during the time of their children's diagnosis. As a result of this realization, I started asking fathers about their involvement and family lives prior to diagnosis.

In addition, as part of theoretical sampling, I probed more deeply into the fathers' experiences with certain important concepts that had appeared in other fathers' interviews. Theoretical sampling is a process grounded theory researchers use to actively engage in their search for relevant data that provides diverse perspectives on the phenomenon of interest (Corbin & Strauss, 2008). Theoretical sampling entails collecting, coding, and analyzing data simultaneously. In theoretical sampling,

researchers do not sample people, but concepts. This means that as researchers analyze data, they seek out additional data sources that will provide either new data (i.e., new concepts) or confirmatory data (i.e., concepts that already exist in the data) that help develop the theory. For instance, as more fathers talked about monitoring their children's treatment, I posed more probing questions about monitoring (e.g., "How do you monitor compared to your child's mother?", "How does your child respond to your attempts to remind her to check her blood sugar?") to other fathers to gain more depth of knowledge about the concept of monitoring. In addition, as some of the fathers revealed information about how they encouraged their children's responsibility in treatment, I asked other fathers questions to probe more deeply into that process (e.g., "How is your child involved in treatment," or "How much decision-making power does your daughter have regarding her treatment?"). Examples are presented in Appendix E.

The grounded theory process included follow-up interviews. As I began to understand more about the families' contexts and processes, I formed a theoretical model about them and their influences on paternal involvement. I performed follow-up telephone interviews with three of the fathers who were my best informers to assess the fit of the model with their experiences and to gain any further information they could provide about the processes that appeared in the model. This process is called member checking (Birks & Mills, 2011). Examples of the basic follow-up questions I asked can be found in Appendix F.

Data management. Interviews were digitally recorded and transcribed. For both in-person and telephone interviews, I used a digital voice recorder that was plugged directly into my computer to download the recordings. I transcribed the interviews by

listening to the audio recordings via a program called Express Scribe, and typed out the interview conversations verbatim. I provided each father with an ID number based on the order in which I interviewed them. All computer files were password protected on my personal computer.

Memo writing. Another method I used to assist in the concurrent data collection and analysis was memo writing (Birks & Mills, 2011; Corbin & Strauss, 2008).

Immediately following each interview, I wrote memos. These memos included specific words or phrases that were particularly meaningful, as well as my impressions of the interaction during the interview. I used the memos as a sort of journal about my feelings and thoughts that arose throughout the data collection and analysis. Memo writing was also important to the generation of theory from data. As I considered the concepts that were emerging from the data and their interrelationships, I wrote memos to record my thoughts on these relationships. These records helped me remember earlier thoughts about the concepts as the theoretical model emerged.

Data Analysis

The first level of data analysis involved open coding (Corbin & Strauss, 2008). The goal of open coding was to extract meanings and themes directly from the interview data. Open-coding is a line-by-line microanalytic process in which the interview data are broken down into smaller units, labeled, and organized into categories based on conceptual similarity (Matta & Knudson-Martin, 2006). I used the QSR NVIVO 10 software to assist with the coding and categorization of the data. A brief example of the coding process is presented in Table 1. As new data were coded and organized, each piece of data was compared with previous categories to determine whether it is conceptually

the same or different. If different, that piece of data received a new label. The further I proceeded with the process, the more the codes loaded into existing categories rather than needing a new category of their own. This was a signal that theoretical saturation had been attained, and no new fathers needed to be recruited. Although it is possible that novel data would have been obtained by recruiting more fathers who were less involved in treatment, fathers from racial minority groups, and fathers from lower socioeconomic strata, the difficulties involved in recruiting such fathers for this study hampered efforts to sample their experiences.

While coding and categorizing data, I used sensitizing concepts from the literature on father involvement. Sensitizing concepts can be useful in grounded theory research as guides to researchers as they fit phenomena and concepts that emerge from interview data into categories (Bowen, 2006), and form their theoretical models from the data. For instance, as I considered the data on micro-level contextual conditions that influenced paternal involvement, the literature base on maternal gatekeeping provided some guidance in understanding how fathers and mothers interacted with one another around their children's treatment. Use of sensitizing concepts is consistent with grounded theory methods because sensitizing concepts are not imposed on the data during analysis. As I analyzed new data, I revised the categories as necessary in response to new concepts.

Table 1: Example of the open coding process

Example Quote (coded phrases are underlined)				
<p>There were times where <u>she wasn't in position</u> to take care of our son because of <u>the babies</u>, so <u>it was me doing it</u>. So we found over time that <u>early morning worked better for her</u> because <u>the rest of the kids were asleep</u> and <u>she was getting up early to go to work</u>, so she could check on him. And when it was <u>dinner time</u>, <u>she was cooking</u>, so it was <u>easier for me to check on him</u>. And at night, I'm the one who stays up late and she goes to bed early, so <u>I'm always up until everyone is in bed</u>, so <u>I check on him at night</u>.</p>				
	Categories			
	Caring for other children	Work schedule/ Sleep schedule	Household labor	Time split
Open codes (codes from other passages in data set are in italics and boldface)	<p>Because of the babies</p> <p><i>3-year-old tries to help</i></p> <p><i>have to keep them separated</i></p> <p><i>Have four other children</i></p>	<p>Kids asleep</p> <p>She got up early for work</p> <p>I'm always up late</p> <p><i>I work 8am to 5pm</i></p> <p><i>She stays at home</i></p>	<p>Mom cooks</p> <p><i>I do all the cooking</i></p> <p><i>I cook dinner</i></p>	<p>Mom not in position</p> <p>It was me doing it</p> <p>Early morning worked for mom</p> <p>Easier for dad to check at dinner time</p> <p>Dad checks at night</p> <p><i>Dad takes over when home</i></p>

As part of the constant comparison process (Corbin & Strauss, 2008), once categories were identified and defined, they were compared to each other to determine similarities and differences. Through this process, categories were combined or renamed. As categories were combined, the categories became more abstract and inclusive of

interrelated concepts. This process was once called axial coding, and was considered a step in data analysis that was distinct from open coding, because it comes after open coding (Corbin & Strauss, 2008); however, recent revisions of grounded theory methods considered open coding and axial coding as concurrent processes that were both a part of constant comparison.

The final stage of data analysis was theoretical integration and generating a theory (Birks & Mills, 2011). Corbin and Strauss (2008) described this process as elaborating the analysis. The goal of this final stage was to identify patterns and processes within the data that influenced the construct of interest, in this case paternal involvement in care. This stage of analysis included creating links between categories or phenomena, relabeling or renaming them as needed, and reconstructing the data in new ways in the process of developing theory. As patterns and processes were identified, I identified a core process, *sharing the responsibility*, which linked family processes to paternal involvement in treatment and care.

Validity and trustworthiness. For considerations of validity, grounded theorists typically apply terms such as trustworthiness, authenticity, and dependability (Lincoln & Guba, 2003). Trustworthiness of the analysis was ensured in three ways. The first method involved triangulation of the data and concepts. Throughout data collection and analysis, the data analysis was evaluated for trustworthiness by triangulating my analysis with other perspectives on the data that challenged my assumptions about the data. I enlisted the assistance of my advisor by having him read the raw data and providing me with his impressions and insights about the data. My advisor also read memos and provided feedback on the developing constructs in the theoretical model.

The second part involved evaluations of the theoretical model. After the theoretical model was generated, it was validated by making sure that it represented the raw data. The model went through several iterations before reaching the form it took for this manuscript. Early iterations of the model were less process-oriented and more linear in nature. Once the model was in a satisfying form, I returned to the raw data to compare the model to the raw data to make sure it “made sense” (Corbin & Strauss, 2008). In doing so, I searched for any inconsistencies between the model and the raw data (i.e., Did the model fit with experiences of the fathers? Did a significant number of the fathers have similar experiences that were not represented by the model?). It was determined that the overall model was consistent with all of the fathers’ experiences, although the influences of various processes on paternal involvement in treatment were stronger for some fathers than they were for others. For instance, one of the fathers (#5) did not report many experiences with encouraging child responsibility for treatment, likely because he was not involved in treatment and his daughter had not become responsible in any way for her own treatment. While re-reading the transcripts, I also collected passages that were representative of the processes in the theoretical model and placed them into a Microsoft Word document. Many of these passages were used in the results section to present the findings. A list of these representative passages can be found in Appendix G.

The final step involved member-checking (Birks & Mills, 2011). Member-checking is a process by which grounded theory researchers return to their participants and tell them about their analysis of the data and the theory that emerged from it. I contacted fathers to present my findings to them and request feedback on the findings.

The processes proposed in the model resonated with the fathers I interviewed and they were able to provide little new information about the processes, which also provided verification that theoretical saturation had been reached (Birks & Mills, 2011).

Chapter Three

Results

Overview of the Theoretical Model

Strauss and Corbin (1998) proposed that the development of a theoretical model from grounded theory methods should take into account the macro and micro conditions that interact to form the context of any phenomena that a researcher seeks to understand. It is within this context that family processes produce outcomes such as father involvement in treatment and care of children with type-1 diabetes. In addition, Strauss and Corbin (1998) emphasized that these outcomes become part of a recursive system that informs the evolution of context.

Throughout the process of data collection and analysis, various concepts and their interrelationships were identified that formed the basis of the theoretical model presented in Figure 1. The upper boxes and arrows in the model comprised the interactions between macro conditions and micro conditions. These interactions produced the context within which various family processes (i.e., depicted in the middle boxes) occurred that influenced how the fathers shared responsibility for treatment with other family members (i.e., depicted in the oval at the center of the model). The fathers' descriptions of how they shared responsibility for treatment with their family members were also used to classify them into types of paternal involvement. The ways and extent to which fathers' were involved in treatment also entered into a recursive process with the development of trust within the parental treatment team.

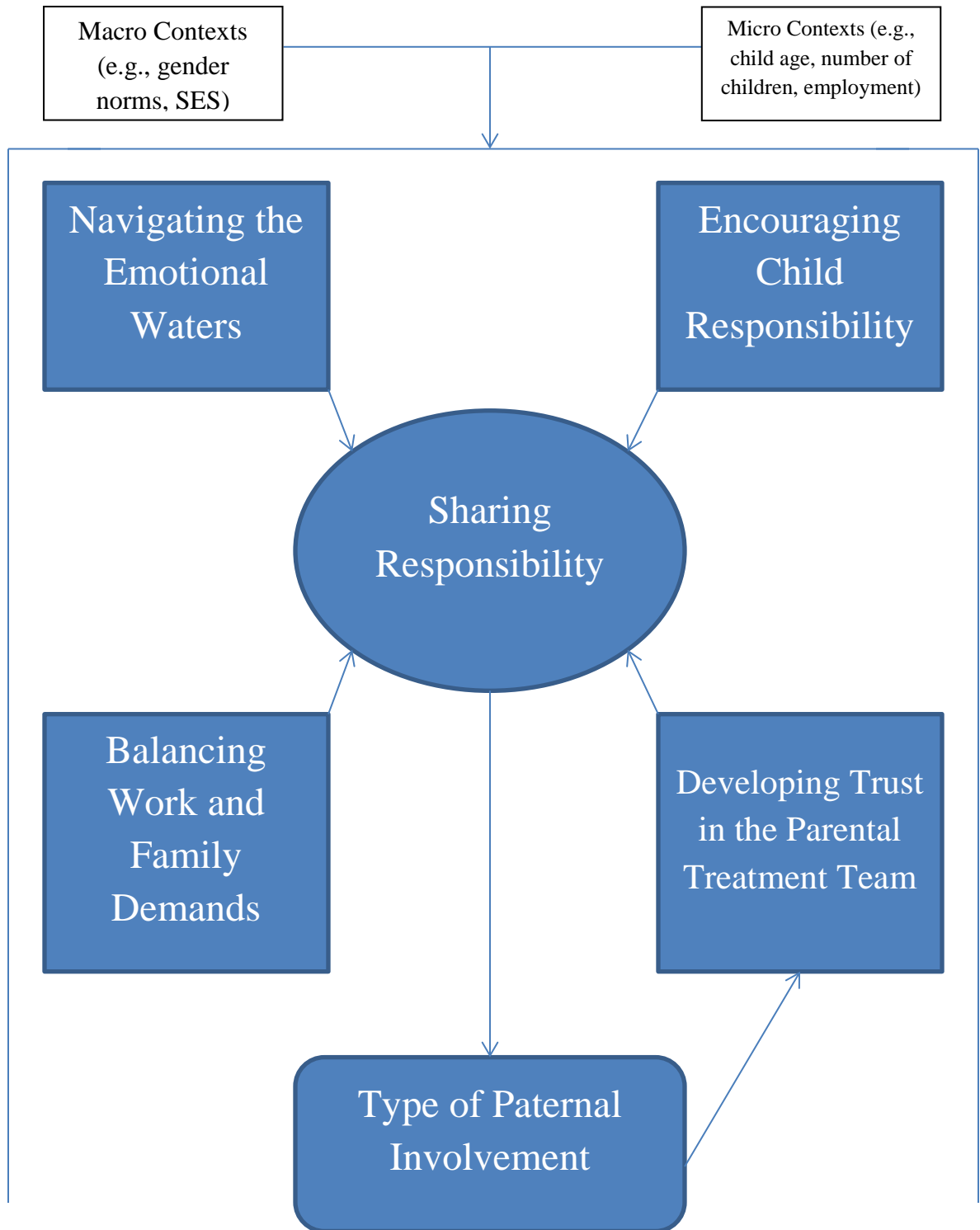


Figure 1: Theoretical model of influences on paternal involvement in treatment and care for children with type-1 diabetes

As parents encountered and adjusted to their children's illness and treatment regimens, the processes they underwent occurred within the interplay of macro and micro conditions. First, their families experienced an emotional upheaval surrounding their children's diagnoses and hospitalization. At times, this upheaval was the consequence of inaccurate diagnoses of their children's illnesses and subsequent delays in treatment that endangered their children's health. The emotions they experienced during this time were connected to how they adjusted to the transition to not only being parents, but now treatment providers.

Families also had to develop a routine surrounding their children's treatment and how they shared the responsibility for treatment. The development of this routine was influenced by how the fathers balanced their work and family demands. The barriers they faced to their involvement (i.e., typically work demands) and their perceptions of their decision-making power regarding those demands intersected with the fact that their families' health insurance often was tied to their employment, and with their job type (i.e., white collar vs. blue-collar). In addition, some of the fathers were aware of gender norms of fatherhood, and they adopted explicit and implicit gender role beliefs in relation to those norms. These beliefs provided motivation for their decision-making, which had consequences for their involvement in treatment.

In addition, the ways the fathers developed trust within their relationship with their children's mother influenced they shared responsibility. The development of trust in the relationship was connected most strongly to the fathers' knowledge and skills related to treatment and their perceptions of their own abilities in performing treatment tasks. In addition, fathers' decision-making about work demands and the degree to which

they kept the lines of communication open while they were away from home influenced the development of this trust. For some of the fathers, the cooperation, or lack thereof, they experienced in their coparenting relationship with their children's mother after separation and divorce shaped the development of trust between them.

Finally, as the parents developed their routines in treatment over time, they encountered the need to encourage their children's responsibility for treatment. Fathers had to determine in what treatment tasks were developmentally appropriate for their children to engage based on their children's age and maturity levels. In addition, as their children gained more responsibility for treatment, fathers modified their involvement to include less direct involvement in treatment tasks and more monitoring of treatment adherence. At times, fathers felt the need to increase monitoring in response to their children's difficulties with overall metabolic control.

In the sections that follow, I detail these processes and the contexts in which they occurred, and explain the recursive system between paternal involvement and building trust within the parental treatment team. I end by exploring how some of the fathers wish to be more involved in the future.

Family and Treatment Processes and Contexts

The story of paternal involvement in the care of a child with type-1 diabetes did not begin once the families returned home from the hospital visit during which their children were initially diagnosed, their health stabilized, and treatment begun. The fathers in this study, including the stepfathers, were all actively-involved parents to various degrees before the diagnosis; therefore, the story of their involvement actually began long before the diagnosis. The diagnosis of diabetes served as a turning point for

the families, and there is evidence of continuity and discontinuity between the family contexts that preceded and followed the children's diagnosis. I will explore the family contexts that existed before, during, and after diagnosis. By these means, the reader will know the full story of father involvement, and not one truncated by an arbitrary beginning at the time point when the families returned home from the hospital.

Sharing responsibility. When the families returned home from the hospital, their treatment tasks included: (1) testing blood glucose, (2) injecting the child with insulin, and (3) tracking glucose readings, insulin injections, carbohydrate intake, and exercise in a logbook. In addition, fathers communicated by phone and text with their children's mothers about how much insulin to inject based on carbohydrate intake, exercise, and glucose readings. Finally, fathers also attended their children's physician appointments, which usually took place every three months.

The key concept in this model, *sharing responsibility*, described how the families decided who would perform treatment tasks and when those tasks would be done. *Sharing responsibility* also included the ways in which families modified the division of responsibilities for the treatment regimen as the children aged and treatment regimens changed. Fathers, mothers, and children, depending on age and maturity levels, engaged in treatment tasks at varying levels over time. I categorized the fathers into types of involvement based on how they shared the responsibility for treatment tasks with their children and their children's mothers. The labels for these types utilized some of the fathers' own language regarding their involvement.

The labels for these types included "not involved" (n=1), "helper" (n=3), "equal partner" (n=6), "treatment monitor" (n=4), and "primary caregiver" (n=1). The father

labeled as “not involved” described himself not being involved directly in treatment tasks. The fathers labeled as “helpers” were directly involved in treatment, but were less involved than their children’s mothers, and sometimes saw their role primarily as that of a helper to the mothers. The fathers labeled as “equal partners” perceived treatment tasks as split relatively evenly between themselves and their children’s mothers. Fathers labeled as “treatment monitors” were fathers who were less involved in direct treatment tasks than some others because their children were responsible enough for their own treatment that the fathers’ and mothers’ primary role was to monitor their children’s treatment adherence. They displayed a higher degree of direct involvement in treatment while their children still needed more help, but eventually they “backed off” from direct involvement and started monitoring more as their children gained responsibility for treatment. Finally, the father labeled as the “primary caregiver” described himself as the more responsible parent and as the “one who takes care of (his daughter).”

Sharing responsibility was not a process by which family members decided consciously to take turns engaging in treatment tasks. For example, one father stated that “I probably give more of them (injections) than she does just because of who is available; it’s not like ‘I took my turn, and now it’s your turn.’” The fathers’ descriptions of *sharing responsibility* sometimes referred to how time spent performing treatment tasks was divided based on time of day, work shifts, the presence of other children, children’s responsibility for treatment, and other household responsibilities.

In addition, when asked about how they decided who would engage in what treatment tasks and when, the fathers reported that there “was no discussion or

negotiation,” and that the division of labor seemed to happen on its own. Two fathers reported, “I think it’s just what evolved, what happened,” and

It’s kind of a natural thing now. It’s not really anything that is spoken. We just, like everything else, if our daughter needs something that I didn’t get a chance to do it, she just does it. And vice versa.

It is possible that fathers simply did not remember any discussions or negotiations even if they happened. In addition, although many of the fathers pinpointed specific contextual influences on their division of labor (e.g., work demands, caring for other children), the notion that the division of labor happened on its own indicates that some the fathers either did not recognize the influence of contextual factors on their family processes or they could not conceive of a way to explain the *sharing responsibility* process.

Navigating the emotional waters and sharing responsibility. The parents’ emotions surrounding their children’s diagnosis and their treatment roles were important to how the fathers created and adjusted to their treatment roles. As one of the fathers stated, “It was mainly difficult with it being a child; it was kind of upsetting. We had to adjust to the emotional side more than anything.” The family emotional context included feelings of abnormality, uncertainty, guilt, fear, and anger. These feelings were evident in fathers’ comparisons of post-diagnosis life with pre-diagnosis life, their recollections of the health crises their children experienced before and during the time of diagnosis, and their reports of the rapid changes in family roles to which they had to adjust when they returned home.

Fathers' descriptions of their pre-diagnosis parenting involvement. The fathers' descriptions of their own parenting involvement were often in terms of play activities in which they engaged with their children; this was the case for all of the fathers in the study. This common experience is consistent with gender norms of middle-class fatherhood, which frequently revolve around play and leisure activity participation. The fathers mostly described play activities such as going to the park, providing "piggy-back" rides, playing with dolls and stuffed animals, and "typical little kid stuff." Some of the fathers also reported that they were involved in athletics activities such as coaching their children's soccer teams and attending football games and practices. Several of the fathers described activities for which they felt they were particularly suited, such as helping with math homework, putting toys together, and taking their children out to the farm, fishing, and camping. In addition, some of the fathers remembered anticipating the fun they would have with their children, particularly through participation in coaching sports teams.

Finally, some of the fathers recalled bonding activities and the amount of time they spent together. Father #14, a "treatment monitor" who worked a job that required long shift work over fewer days a week, described how his special bonding time with his daughter occurred when he would come home after midnight and feed her when she was an infant. He described that time as what probably helped the two of them become close later in life.

I was in... police work when she was born, so that involved a lot of late nights. I would get home at about 1am or 2am in time for her feeding in the middle of the

night. And we'd stay up until about 3am or 4am. That's probably where our bonding started.

Father #11, who was an "equal partner," emphasized the closeness that came from spending a lot of time with his wife and daughter.

We were a pretty close family. We really didn't pawn off our daughter on grandparents or anything of that nature, or babysitters. We really included her in our lives and changed our lives around her. She was pretty portable, is what I always said. Pretty portable.

The closeness these fathers reported was a factor that motivated their involvement in treatment. In fact, pre-diagnosis father involvement was connected to post-diagnosis involvement. Fathers who described being more involved in parenting activities (i.e., play and leisure, spending time with child) before diagnosis tended to be more involved in treatment after diagnosis. Fathers who described being less involved in parenting, or did not describe their involvement before diagnosis at all, were less involved in treatment post-diagnosis.

Comparisons of pre- and post-diagnosis family life. Several of the fathers recollected their families before diagnosis in an almost wistful manner, as though remembering better times. They described their families in terms of them having been normal and average, as though comparing the past with their post-diagnosis life, which was no longer normal or average. For example two of the fathers stated that, "everything was normal," and it was "just average everyday life, you know, going 100 miles per hour."

In the past, many of the families were able to live life more freely than they were able to after the child's diagnosis, but their daily lives when they returned home from the hospital revolved around a sometimes-rigid schedule of eating, glucose monitoring, injecting insulin, and tracking them in a logbook along with recording carbohydrate intake and exercise. The change in lifestyle was tangible for Father #10.

A typical day was that we ate what we wanted, when we wanted. We didn't schedule activities around meals. It was like anyone else who doesn't have diabetes. It didn't matter, we were an active family all of us. Did a lot of things together. It didn't matter when we were doing whatever, we could stop and get a bite or not.

This change in lifestyle complicated the families' engagement in many activities either through the need to be sure they carried diabetes treatment supplies everywhere they traveled, tested glucose in the middle of athletic competitions, or ensured that their children ate at a certain time to avoid hypoglycemic episodes (i.e., low blood sugar), which usually meant that the rest of the family ate at the same time. Scheduling life around treatment may have been seen as a challenge in which fathers actively engaged or avoided by withdrawing into work or other activities. These perceptions of a lack of normalcy may have combined with the other emotions the families first experienced during their children's initial health crisis and hospitalization to create a complicated emotional context in which the parents and children settled into their new treatment roles.

Response to first signs of diabetes. The manner in which the parents responded to their children's first symptoms of diabetes seemed to be determined in part by whether they had any previous knowledge of the symptoms of diabetes. One of the fathers was

diabetic himself, while others had family members who were diabetic. Some of these fathers (n=5) were able to recognize the signs of diabetes and were quick to check their children's blood sugar, either with their own or a family member's supplies, or bring them to their physicians for a diagnosis. Some of the fathers (n=3), however, were either unaware or only had a vague awareness of the symptoms beforehand, and waited for several days or weeks before bringing their children to the physician. During the interim, they observed symptoms such as their children being "always hungry" or "always thirsty," or leaking through their diapers and wetting the bed. They also observed weight loss in their children that was surprising and unexplainable at the time because their children were eating large quantities of food. Some of the fathers also recall their children not feeling well for several days or weeks at a time, and one of the fathers of an older child remembered his daughter "not being herself."

Among the fathers who were previously unaware of the symptoms of diabetes, several (n=6) recollected attributing their children's symptoms to something other than diabetes. One of the fathers who reported that his older daughter had mood swings and was being uncharacteristically rebellious remembered thinking that "maybe at 13 this would be normal."

For Father #9, his child's diabetic symptoms were seen as attention-seeking behavior:

We were headed to a funeral and on the way down our son continued to ask for a drink. On the way down there he drank about a liter of Powerade. Mind you he's only two, so that's quite a bit of liquid for a 2 year old that weighs 30 pounds. But

we didn't think anything of it, we thought he just wanted the attention or just liked the sugar and the Powerade.

Sometimes, though, the symptoms accompanied other illnesses and were mistaken for symptoms of those illnesses by both the parents and their children's physicians. Father #6 recalled the following:

We thought it was a cold, but the week before she got to where she was getting thirsty, so we took her to the urgent care in Joplin and they diagnosed her with the croup. They said if anything happens with her get her to the emergency room.

These misattributions of the symptoms resulted in significant delays in the children being diagnosed with diabetes and receiving the treatment they needed to stabilize them. The delays for some of the children were so significant that the children's illnesses progressed to the point of a major health crisis (n=5). Some of these fathers reported that by the time they brought their children to the emergency room, their children's blood glucose readings were so high that the meter did not provide a number, but read "HIGH." Some of the other fathers reported that their children's blood glucose read in the 600's and 700's. Many of the children displayed symptoms of diabetic ketoacidosis (e.g., unexplained weight loss and difficulty breathing), which results from ketones building up in the blood due to a lack of insulin and the body burning too much fat for energy (American Diabetes Association, 2013). This condition can result in diabetic comas and death. With their children in such dangerous condition, many of the parents experienced high degrees of fear. Father #6 expressed that "It was terrifying. They told us in the emergency room that she had a 50/50 shot to live. We were scared she would die."

The fear that some of the parents experienced during this time was accompanied by guilt and anger, both toward themselves and toward their children's physicians. Father #15 recalled the following:

Yeah, he was really laboring with his breathing. When the nurse said it was diabetes and we should have gotten him there sooner, my wife kind of lost it because we had been sitting in that waiting room for an hour and a half before he got in. I was very concerned for our son. I was upset with us too, inside, but really upset with the doctor. That's what the doctors are for, to try different things instead of just saying it's flu and sending him home with medicines.

Two of the fathers experienced guilt for similar reasons, but also worried that they had somehow caused their children to develop diabetes. For example, one of the fathers stated that he felt guilty because he "was probably the reason she's diabetic, because it's through the genetics." Father #2, an "equal partner," thought he caused his son to develop diabetes through his own actions.

Well, the initial thing that happened was he ended up being in intensive care for a couple of days. He was pretty bad. I at first felt guilty for him to go that long, I felt I should have saw the signs earlier. So there was a guilty feeling on my part, ummm, and I also feel like because I didn't make him eat well enough and things like that, I felt like it probably made it happen.

The guilt many of the fathers experienced and shared with their children's mothers was, of course, unjustified, and the fathers who experienced guilt remember their children's physicians reassuring them that it was not their fault. Whether their guilt was

justified or not, it provided some motivation to be involved in treatment, as did the anger they felt about their children's conditions.

Although most of the fathers expressed a wide range of emotions surrounding their children's diagnosis and treatment, only some of the fathers (n=4) displayed awareness of how these emotions contributed to the way their families adjusted once they returned home. Two of the fathers ascribed more intense emotions to their children's mother. Father #10, a "treatment monitor," focused on his wife's overprotectiveness by stating that "she didn't want him to leave the house." Father #5, who was "not involved" in treatment, reported that his wife was more emotional and obsessive about treatment. He stated that "she lets it identify who she is. I think she lets it absorb her." These fathers' ascriptions of high emotionality to their wives could be tied to their gender role beliefs. Both fathers expressed traditional beliefs about work and family roles. They both referred to themselves as breadwinners, although Father #10's wife was employed full-time, and Father #5 considered breadwinning to be his primary role. Both men seemed to acknowledge that women are "naturally" more emotional.

Recognizing the child's mother's emotionality did not result necessarily in emotional withdrawal for fathers. The experience of being a support to his wife was important to Father #9, an "equal partner" who saw himself as a strong leader for the family. He recalled an incident in which he supported his wife through her anxiety and difficulty adjusting to the treatment tasks immediately after the diagnosis.

My wife went to work on that Saturday because she had been out of work and works on a commission. I'm on salary and had vacation. So I stayed home and handled the first day by myself. And then when she got home, I kind of helped

her. Being the mother, she was really worried and really analytical when it came to “Am I doing this right? Am I missing a step?” So I just tried to be there for her and calm her as much as I could, and walk her through those things.

One other father (# 6) acknowledged his shared emotional experience with his wife when they returned home.

We were probably a bit overprotective ‘cause we didn’t know that much but we were scared to death. So we were checking her quite a bit. With the finger pokes we probably went a little overboard on that. But after we got into it, and we’d made several calls to the doctor, we wound it down pretty good after that. We were just checking her sugar every three hours, doing the correction shots we needed to do.

Balancing work and family demands, and sharing responsibility. One of the most robust family processes connected to how the family shared the responsibility for treatment tasks was “balancing work and family demands.” The process of *balancing work and family demands* included interactions between several macro and micro conditions. Although fathers often stated that the division of labor “just happened” or “evolved” on its own, several of the fathers’ reports of how their families shared the responsibility for treatment tasks contained stories of the balancing act between work schedules, caring for other children, sleeping, and shuttling their children to activities. The influence of gender role norms and beliefs was apparent in fathers’ stories, especially regarding how their gendered beliefs contributed to their decision-making about their priorities. During follow-up interviews, fathers expressed their beliefs that decision-

making and deciding on priorities were the most important aspects of balancing work and family demands.

The balancing act became apparent to fathers even while their children were still in the hospital. For example, Father #12 reported how he could not be present at the hospital because of work. Other fathers recalled how the need to make sure their other children received care contributed decisions about who was at the hospital and who was at home. Grandparents and other family sometimes watched other children, but three of the fathers recalled how they had to split the time they spent at the hospital with their wives so that they could ensure that one of the parents was watching the other children:

We switched off nights. We had a newborn, so we had to take care of her. I'd go home with her, we'd come back together the next day and my wife would go home with our daughter that night while I stayed in the hospital with our son.

When the families returned home from the hospital, a variety of factors surrounding work demands and family demands interacted to contribute to the division of treatment tasks. For one of the "helper" fathers, Father #8, providing care for the other children while the child with diabetes received help with treatment was a continuous need.

I was trained for it, and uh, just haven't had an evening routine when it gets changed. I'm usually taking care of our other daughter when it gets done. It's easier if the kids are separated when that's happening because the little one wants to get involved with it and help out (Laughs).

Father #9, an "equal partner," provided the following description of how time performing treatment tasks was balanced within work, eating, and sleeping schedules:

So typically now it looks like, since she stays at home with the kids, she'll give them breakfast, give him his breakfast shot, give them lunch, give him his lunch shot. And then when I get home, I'll usually help make dinner, and then give him his dinner shot. And then I'm typically the last one up in our household. I'm a full-time student as well as working. So usually I'm in online classes, and when I'm done and getting ready to go to bed, I'll give him his night shot.

For Father #2, another "equal partner" who worked three or four 12 hour shifts per week, the balance included his work schedule, his children's school and eating schedules, and the occasional need for his wife to call him while he was at work to discuss the dosage of insulin to give their son when his blood glucose ran high.

If they're going to school and I go to work, I check his blood and give him a shot in the morning, and I'll usually write that down because he can see where it was. And then, I'm gone the rest of the day because I work 12 hour shift, so he will walk out and meet the bus for school. Mom makes breakfast and then makes his lunch; he doesn't like to eat school lunches. At school, he just does a blood check at lunch, and then when he gets home usually before dinner he'll do a blood check and then mom and he will try to figure out how much insulin. If this blood checks high, they'll usually call me and I'll try to tell them what insulin he should take.

This father was nearly a "primary caregiver" because of his frequent communication with his wife about insulin dosages, which he said was necessary because his wife did not seem to understand how to calculate the dosage. He stated at one point that he felt a lot of the "burden" of care was placed on him because of his wife's lack of

knowledge and his son's lack of personal responsibility for treatment. However, he also stated that time on treatment tasks was split about evenly.

Father #6, a "helper" who worked full-time while his wife was a stay-at-home mother, was in a similar situation in terms of how his work schedule played a role in when he was home to perform treatment tasks. In addition, he provided information about how the division of time shifts based on temporary needs such as illnesses, household tasks, and his wife's need for a break after being home with their children all day.

Now, she stays home during the day while I'm at work, so she takes care of her through the day, and I get up and check her at night, give her shots and such. I mean when she's sick, or when I'm sick, we'll change it. She'll get up in the middle of the night. Lately we've been doing a lot of work on our house, so it's been really hectic, but I still get up and check her... Chris does the majority of the housework. I get home around 5-ish. We eat dinner, then play with the kids, watch a movie sometimes. Sometimes she needs a break after being with 2 kids all day long. She may go spend some time with her friends. Well, when I get home earlier on Fridays I get to help out a little more. So that helps out, I can give her a bit of a break. She's at home with both girls, she can't watch Paige outside. I don't like Paige being outside by herself... What hinders my involvement is working overtime, or if I have to go out of town. If I have to go out of town, I don't know what's going on except for phone calls.

For this couple, their gender role beliefs also played a significant role in how they chose to divide responsibility for treatment tasks. The father described how he and his

wife had been looking for a reason for her to quit her job and become a stay-at-home mother. When their child was diagnosed with diabetes, they found the reason and the mother put in her two-week notice as soon as they returned home from the hospital. Their desires for her to be a stay-at-home mother, in addition to the father's statement that his wife does most of the housework and that his returning home from work is her time for a break from the children (i.e., her work as the primary caregiver), are indicative of traditional gender role beliefs. This father was a "helper" to the mother not only because she did more of the work, but because he saw his role as that of a helper who gave her respite from her primary job.

One "equal partner," Father #11, who displayed awareness of changing ideals toward more egalitarian gender roles in caregiving (i.e., "We're more involved in caregiving than 30 years ago"), explained how he and his wife shared responsibility for treatment based on work schedules, household work, and his child's increasing responsibility:

Well at various times, one or the other of us has taken the lead. I always pretty much took care of her in the mornings. We'd both get up and go to work. So for example, I would get up first. I tested her sugar, gave her shot. And this happened every morning until she started giving herself shots. At noon, depending on where we were at, Jennifer took some time off to take care of Quinlyn. In the evening, Jennifer would make a meal and then I would check the blood sugar and give the shots.

Being an "equal partner" did not necessarily include awareness of gender role norms and beliefs for all of the "equal partners." For some couples, the nature of their

dual-earner households and work shifts required a more equal sharing of roles. Another “equal partner” father, Father #13, in whose family both of the parents worked full-time jobs in opposite shifts, explained how they divided treatment and household tasks based on who was at home at a given time. This father was not highly invested in traditional gender role beliefs. Their caregiving arrangement was more a matter of necessity and convenience than it was about ideals:

Well she works nights and I work days. Whenever she was home she would do a lot of it (insulin injections and glucose monitoring), whenever I was home and she was working, I would do a lot of it through the night and in the morning... We basically do a lot of the carb counting because we’re usually making dinner anyway, so we do the counting then.

For Father #3, an “equal partner”, the balancing act became more about sports and other activities in which his daughter was engaged. This father was in a dual-earner family, but in the rather unusual situation of his wife being a consultant who was out of town for weeks at a time. The father worked full-time in his own business, but spent a large amount of time in the afternoons and evenings making sure that his daughter had all of her treatment supplies available while she was involved in her activities. He also made sure she ate when she needed to, despite the inconvenience.

We put a stash here or there, so that no matter where you are, you have some.

We’ve already had situations where I thought she grabbed it, she thought I grabbed it. And we’re up here and getting ready for a baseball game and whatever, and now we have to go home, get her insulin, get her back, feed her.

We have all these timing issues where they have to eat within 30 minutes of

taking insulin. Eating needs to be at about the same time each day. And now she's started track and they had their first meet, and she needs to bring food to eat, and take her shot. The meets are over at 7:30 or 8:00 pm, so we're already an hour past. The doctor stressed the day I met you that she has to eat more consistently. All the kids are sportsy, it throws off our eating schedule. She has to just eat when it's time, the others have to just eat when they can.

Decision-making regarding work demands. Within the balancing act between work and family demands, flexibility of work demands seemed to hold the most prominent place in the minds of the fathers. Although some of them found ways to be involved in treatment even while they were "on duty" (n=3), mainly by communicating with their child or their child's mother by phone or by briefly leaving work to take care of their sick children, many of them saw their work schedules as a hindrance to their involvement. Two of these fathers made statements such as not seeing how they "could possibly be more involved in treatment" because of work. They seemed to see work as an intractable presence in their lives over which they had little control, while others recognized that they had some control over their work demands. Some of the fathers exercised control while some did not.

Among the fathers who were "equal partners" (n=5), and to a lesser degree amongst the "treatment monitors" (n=1), there was a general consensus of high flexibility in their work demands. Many of them perceived that their employers were supportive or flexible enough for them to be able to take off from work when needed to take their children to doctor's appointments or leave work to tend to a sick child. Although many of these fathers needed to give notice to their employers, a couple of them were high

enough in their hierarchies at work that they could leave work whenever necessary unless there was a major meeting at which they had to be in attendance.

To Father #2, an “equal partner,” the supportiveness he felt from his employers was important to his perceptions of flexibility:

The good thing about the department I work for is if there is some sort of family matter or something you need, they go out of their way to make sure you get what you need or whatever. Since I work 12 hour shifts, I have a lot of days off so scheduling our appointments on my days off is not very difficult. And if there’s something I do have to go to on a day I’m supposed to work, if I have enough notice, it’s easy to get that time off. So that works well.

To Father #11, an “equal partner” who worked in an executive position, the flexibility was a little more under his control. Although he perceived that his employers were supportive, he was able to take the time off virtually whenever he needed to, without notice, except when he had work that absolutely had to be finished, in which case he still made sure his daughter was cared for by a family member while he returned to work.

Having an office job, there are times I have meetings that I have to go to, but I also have some flexibility. So I can take extra time during the day to check on her, or fill some demand. I have more flexibility than a lot of people do. Unless I have to give a presentation or something, even if I’m in a meeting... for one thing we got our daughter a cellphone when she was young. So she can send me a text and I text her back. I can step out of a meeting for a few minutes to talk to her. So far every place I’ve worked, they have been understanding and it hasn’t created any

issues... One time when we were in Ozark, the school nurse had to call because she wasn't feeling well. So I just packed up and went to get her, spent the rest of the day with her. When I can't do that, I may take her over to her grandmother's house while I finish up a few things at work. I can also use it to go to the doctor's appointments every few months.

Flexibility in work schedules was not always present for "equal partners." For example, Father #9 made the decision to change jobs so that he could have more flexibility to care for his child:

My work is flexible now. When he was first diagnosed, it wasn't. I was sales manager at a retail location. When I was there, I was there. I was usually there anywhere from 5:30 am to 7 pm. Now I have a more flexible schedule. I'm on the road, but I have time to check in with the kids and call the wife and talk to her. Sometimes I work out of the house, so I'll be on the laptop at home, but at the same time if the kids want to come in and talk, I'm there for them... The job I took is a lateral move. It wasn't a promotion, just a different channel of the business. But I knew it would give me a little more flexibility for family time.

Other fathers in the study (i.e., helpers, n=3; treatment monitors, n=2) did not perceive much flexibility in their work demands. Working from home would seem to be an easy solution to the flexibility problem for fathers who work in "white collar" jobs, but it was not that simple for some of the fathers. Father #8, a "helper" who often worked from home, did not perceive flexibility in his work demands, even while working from home. He stated that "I have a flexible schedule, so I'm able to provide some help when I'm at home working, but not that much... I can't do it as much while I'm actually

working on the phone or computer.” This father perceived some flexibility to take time off when needed to go to doctor appointments, but later he recognized that even when he was home, he would “sometimes help... sometimes not do anything” because of his demands while working from home.

The lack of flexibility was partly based on the type of employment. For fathers in “white-collar” jobs, decision-making entailed changing jobs, taking time off from work when necessary, or deciding when to help while working from home. “Blue-collar” workers, however, may have more difficulty than “white-collar” workers in making decisions about work demands. Because many of them do not receive pay when they are not at work, they may see little choice but to keep working, even during a family health crisis. “Blue-collar” workers may also have workplace policies that are inflexible.

Fathers in “blue-collar” jobs in which they were paid hourly did not perceive flexibility in work hours. Because these fathers were paid by the hour, going to clinics or hospital appointments could be expensive. One father (#12) reported that “I don’t go to a lot of the doctor’s appointments because where I work if I’m not there I don’t get paid. She works salary for the court system. So she can take off time.” This father was also not able to be at the hospital during his child’s initial stay because of work.

On the other hand, “white collar” employment did not always necessarily entail work flexibility. Three fathers (i.e., two “treatment monitors” and one “not involved”) perceived very little flexibility in their work demands. The two “treatment monitors” both owned their own businesses, but found themselves working long hours. These “treatment monitors” had wives who were employed full-time, either working in the

businesses they owned or in another job. Father #4 considered himself to be at the mercy of his clients because of the nature of his work.

We get tied up getting involved in getting everything done. We don't download her pump as often as we should so we can help her stay on top of her sugar.

When you own your own business, it's a busy thing. It takes overtime, which keeps you from spending time with your family. There again, the people we deal with to me are kind of like family too. Our kids understand that. That's one thing... they've always been involved in our business... We own funeral homes in 3 small towns, and so I hate to be this way, but we're at everyone's mercy.

We've been married 25 years, and had one vacation. We don't take vacations. If someone dies, you take care of the family, take care of what needs to be done.

Father #10 framed his focus on work as if it was a matter of choice, but he worked long hours nonetheless:

I would much rather retire early than work into my late 60's. So I would rather bust my butt now and make sure we don't have any overhead or debt. So it hinders it; I'd rather be in an RV with my family. I can't say it doesn't hinder it, because it does. And the only reason it hinders my involvement is because I want to be with my kids and do stuff with them right now. I feel like the responsibility wouldn't be so much of a burden for him if someone were home during the day. He may not feel so "I don't want to give the shot." It's like some days you don't want to go into work but you have to.

Both of these fathers had children who were old enough to be responsible for their own treatment, and their children were required to become more responsible soon after their diagnoses because both of their parents worked full-time.

Finally, Father #5, who was “not involved” in treatment tasks, reported that his lack of flexibility was because of frequent travel, a lack of supportiveness from his boss, and because of his own decision-making.

I've always been a workaholic, work probably 60-70 hours per week ... I think with the way my job is, I'd still be less involved. If my job changed and I was home more, I'd probably be more involved. I think my wife wants me to be more involved, do a lot more things, but I've said to her you can't travel 6 days a week all over the states and be more involved ... I work for a guy who has never once asked about my daughter. If I called him up and told him I need to go to Columbia for a week, it would not be a good conversation. I could make it work, but it would be difficult. It's a decision I've made though.

The choices fathers make about their work demands may have been influenced by their fear of losing their health insurance and their gender role beliefs. For fathers who were employed full-time while their child's mother was not, their families' health insurance was tied to their employment. These fathers may have perceived little agency in their employment situations because they feared losing their children's insurance benefits and the ability to provide them with adequate medical treatment. Father #5 stated that he never wanted to hear that a treatment was available that they could not afford to provide, so he saw his role as earning money to be able to pay for whatever

happened. Father #6 stated that he didn't see how he could "be more involved because (he) cannot quit (his) job."

However, health insurance being tied to fathers' employment was not enough to skew decision-making toward prioritizing work demands. After all, every father in the study was employed full-time with benefits, yet many of them made decisions to prioritize their direct care responsibilities over work demands although the pressure to work was on them because their children's mothers were not working full-time. When fathers believe in the traditional gendered "breadwinner" role, their decision-making regarding work demands may be skewed toward working harder at their jobs. As Father #5 stated, "a father's role is to work 100 hours per week" to provide monetarily so that his child had the best care available. In addition, fathers who adhered to "breadwinner" role beliefs were also more likely to have wives who did not work outside the home, which fed back into the pressure they felt to stay employed.

Even fathers who wanted to be involved in treatment activities often chose work over treatment. For instance, Father #15 reported that he saw his primary role as that of "breadwinner," but he wanted being involved in treatment to be a priority. This could be because he promised himself to be more involved than his own father had been.

My father worked two or three jobs to take care of the family, so he wasn't around much. I promised myself I would be more involved if I had the time.

Thankfully, I have had the time, so I'm involved everyday unless I'm gone on a trip.

Developing trust within the parental treatment team and sharing responsibility.

How the parents shared the responsibility on treatment tasks also was influenced by how

they developed trust within the parental treatment team. As with any team, the degree of teamwork in which the parents engaged when they returned home from the hospital was predicated on the trust they developed in one another. The parents learned whether they could trust one another to perform various treatment tasks both on schedule and correctly. The trust they felt was important because of the high stakes involved in performing treatment tasks, and because it affected how much the parents wanted one another to be involved. As Father #9 explained,

She trusts me when I'm home alone with him, and I trust her. I don't try to undermine her and ask her a bunch of questions to make her feel like I don't trust her to do her job. We're a team and we do what we need to do.

Fathers' ratings of the quality of their relationships with their children's mothers.

Although some of the fathers spoke early and often of their relationship with their children's mothers, the topic of the parental relationship was most often broached by asking the fathers about how they would rate the quality of their relationship with their children's mothers. Thirteen of the fathers in the study rated their relationship with their children's mothers as "good" or "excellent," and two of the fathers rated the relationship as "fair" or "poor." The fathers' ratings of their relationship quality were strongly connected to the way they perceived their parenting relationship surrounding treatment. Most (n=11) of the fathers who rated their relationships as "good" or "excellent" described a "teamwork" style of relating around their children's treatment. Other fathers (n=4) who were mixed in their ratings of the relationship (i.e., two rated the relationship as "poor" or "fair," while the other two rated the relationship as "good") described a parental relationship in which either they or their child's mother "took over" treatment, or

they were more responsible for treatment tasks than their child’s mother once they returned home.

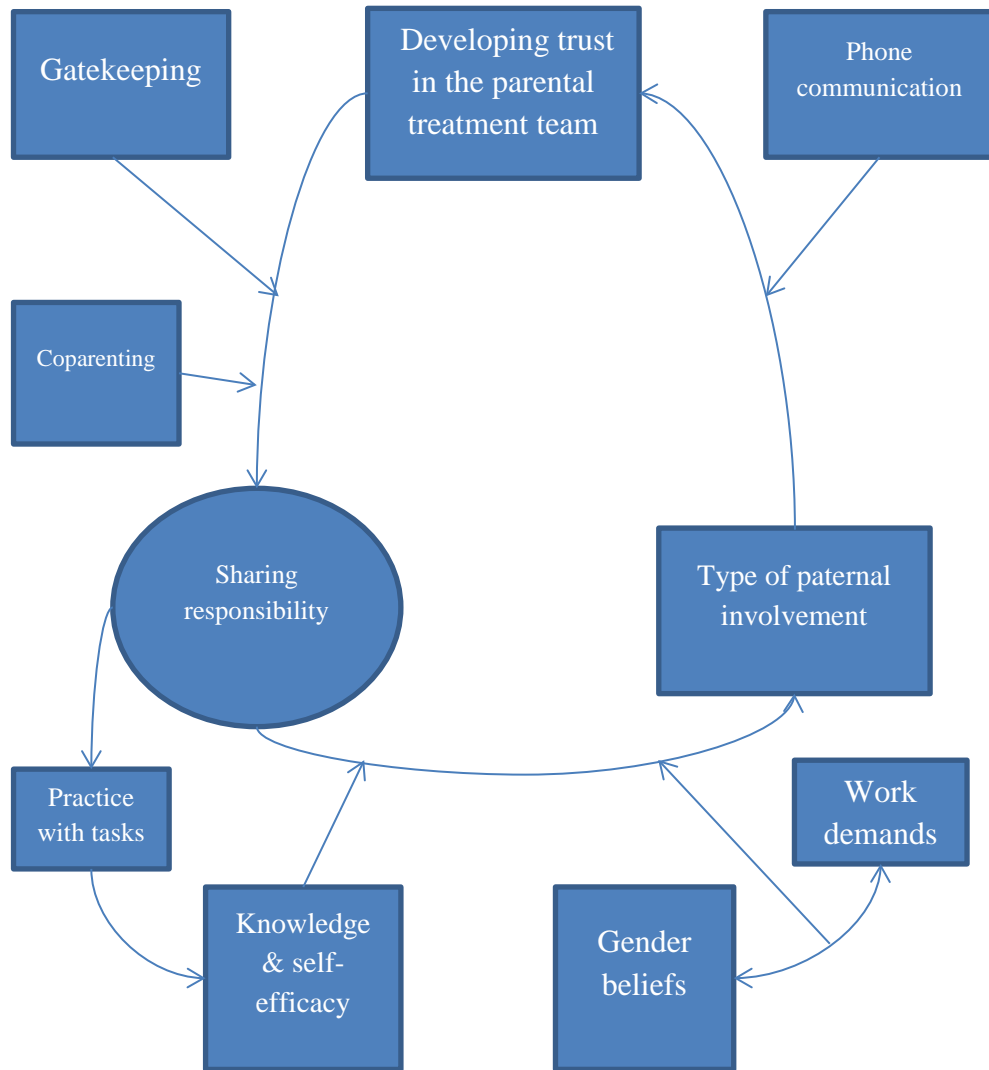


Figure 2: Detailed model of the recursive relationship between paternal involvement and building trust within the parental treatment team, with contextual conditions included.

Other micro conditions seemed more salient to the development of trust in the parental treatment team than did the fathers’ perceptions of relationship quality. Fathers’

perceptions of knowledge and self-efficacy seemed to be the most salient of these conditions. When fathers perceived high degrees of knowledge and self-efficacy, they tended to be more involved in treatment and their children's mothers trusted them to be involved. When fathers perceived low degrees of knowledge and self-efficacy, they were likely to be less involved in treatment and their children's mothers performed some gatekeeping due to their lack of trust in the fathers (i.e., this was also true when fathers perceived their children's mothers to be less competent in treatment than themselves). This gatekeeping resulted in less sharing of responsibility, which fed back into fathers' lower involvement in treatment through the lack practice they received in performing treatment tasks, and lower perceptions of knowledge and self-efficacy. When gatekeeping was absent, parents shared responsibility for treatment and fathers perceived greater knowledge and higher self-efficacy and were more involved in treatment.

The fathers also described how they communicated with their children's mothers while away from home (i.e., more involved fathers communicated with their children's mothers more frequently than did less involved fathers), and the importance of that communication to developing trust. In addition, four of the fathers were in divorced, separated, or remarried relationships. The way they cooperated within their coparenting relationships in these contexts also had some bearing on the connection between developing trust and sharing responsibility for treatment. Finally, there was some evidence that an interaction between gender role beliefs and work demands played a role in how the parents built their treatment team. A detailed model of these factors, recursive processes, and relationships is presented in Figure 2. This model was created because

these processes and factors seemed to be highly important to the practical implications of this study.

Knowledge, competence, and self-efficacy. The relative knowledge about treatment between parents was important to the formation of trust between parents. This was confirmed during follow-up interviews as well. When the fathers described a high degree of teamwork in the parental treatment team, typically they described themselves and their child's mother as being knowledgeable, competent and efficacious in treatment tasks. The descriptions did not always indicate equal knowledge, competence, and self-efficacy between parents, but the fathers still considered their wives and themselves to possess enough knowledge to be effective in performing treatment tasks. For instance, Father #3, whose wife traveled frequently for her job, described how he considered his wife to be more educated than he was about treatment, and how he valued her help.

She can't do it herself, so I go do all the stuff with our daughter and the teachers, and then consult with her. She's more the educated one that when I come back with everything I've learned from them, she'll think of questions I didn't think of asking, and I'll make a note of it to call them to ask. She helped me a lot when our daughter was sick, helped with the formulas to figure out how much Humulin R she needed.

Father #15 described how his wife insists on him attending doctor's appointments because she feels more comfortable with him asking questions of the physicians due to his higher level of education and knowledge.

With wanting me at the appointments, I think she doesn't give herself enough credit, but because I have a college education and she doesn't, I think she feels

that I can understand what the doctor is telling us better and ask the right questions.

On the other hand, some of the fathers described how one parent was less knowledgeable, competent, and efficacious to the point that there were reservations about that parent's abilities to perform treatment tasks. Fathers in these situations did not describe the parental treatment team as being teamwork-oriented. Either one parent tended to take over treatment or one of the parents perceived more responsibility treatment tasks than the other.

Father #12, a "helper," considered himself to be less knowledgeable and had lower self-efficacy with his stepson's treatment tasks than did his child's mother. He described particular deficiencies when it came to changing the injection sites for his child's insulin pump. His fear of failing at treatment tasks and his resulting lack of involvement seemed to lead his wife to take over treatment, and he seemed satisfied with that arrangement because it kept his wife from "gripping" at him when he did not perform tasks correctly. The mother here also may have been engaging in some gatekeeping by taking over and chastising the father, which did not provide him with the encouragement to learn the skills through practice. This instance provides an example of how father's involvement and mother's involvement could be interrelated and recursive.

If we have trouble with a pump, or need to change an injection site, my wife handles it. I have a fear of tearing it up or doing it wrong. The last two times I changed one, the first one I put on each time was bad. It wouldn't take the insulin. I can do it, but I like to have her do it, that way she doesn't gripe at me in case I tear it up.

Father #2 (i.e., the “equal partner” I considered classifying as a primary caregiver because of his descriptions of feeling overburdened) described how his wife did not comprehend the treatment tasks well enough during the training they received in the hospital, and that resulted in him having to guide her through the treatment tasks, particularly in calculating appropriate insulin dosages.

I kind of caught on to the training quicker than my wife did, she didn't really catch the concept of how to adjust the insulin and such, so we had to kind of continue that ... she went to all of the same classes as me, we went to the same training, but she just wouldn't get it. And it hit the point sometimes where it's like “I can't do it all. You're going to have to understand this” ... It's not just with the diabetes, but the way we take care of everything, a lot more of it is left to me. And especially since she doesn't really understand how that insulin responds in his body, so he'll still have to call me. I think it's just her inability to treat or tell him what he needs when there is a problem creates more pressure for me, 'cause sometimes if I'm at work and they call me, I can't answer right then or I can't call right back. So it's something I need them to take care of, and I need them to take care of it properly.

Teamwork after a divorce or separation. For Father #7, a “primary caregiver” who was in the process of an adversarial divorce at the time of the interview, there was a strong interaction between his perceptions of his child's mother's knowledge and competence, and the coparenting relationship they established. This father reported frequently during the interview (which at times seemed like a deposition for a child

custody dispute) that he did not trust his wife to provide treatment for his child, and that she frequently had to call him for help in calculating insulin dosages.

I went through all the schooling and everything, and we stayed there that week by ourselves. Her mom came up on that Saturday night, and we left on that next Sunday. From then on, I'm the only one that's taken care of our daughter. Her mom always has to ask me what to do, or how much insulin she needs ... Her mom has stepped up lately because she didn't have any overnights until last year, and because I didn't feel she had the ability to take care of her.

He also reported that he and his child's mother had difficulty cooperating on treatment tasks that were supposed to be shared, such as filling in and transferring the logbook in which they tracked glucose readings, insulin dosages, and carbohydrate intake.

I've asked to know what her numbers are. We're supposed to be taking a notebook back and forth so I can see where she is at, but I haven't seen the notebook in two straight months. I asked her, and she said "Oh I forgot it." I ask her mother, and she says "You keep the notebook at your house and I'll keep mine". That's not what the guardian ad litem asked, she told us to transport the notebook back and forth. I've seen what's in that notebook, there's not enough information there. There's a lot of highs with no corrections.

A divorce or separation did not necessarily result in difficulties in cooperating between former partners, however. Father #10 described how he and his child's mother cooperated well with one another, even after separating and marrying other people (i.e., they were never married). In fact, the father was effusive in talking about how both sides

of the family “get along” and even spend time with one another. When I asked the father why he thinks the family is able to cooperate with one another, he stated that it was because they always “put (their) son first.”

Our big thing is flexibility, and we are very flexible for each other’s families.

Cameron has siblings on the other side too, Kellen and Miranda. Cameron is the oldest of 5 siblings. He’s always been involved in everybody’s upbringing and stuff, so birthday parties, we all spend together; family events we all spend together, you know Christmas Thanksgiving, Easter, Mother’s day, it’s always been an open door policy between both families. Everything works out well.

For this family, the differences between how the two households handled treatment were respected, and they set up a system for making sure each household had what was needed for their child to manage treatment.

Each family had a different take on it of how they were going to do it, but the end result was still the same. When he’s at Nicole’s, this is how they do it, when he’s at my place, this is how we do it. It’s basically the same thing we learned in the classroom; we just took it home and applied it. We listened to everyone about how this would affect him, and how to keep the negative things at bay. Are we going to have two sets of insulin? Are we going to have dirty needle drops at both houses? We decided we should have a traveling system. As for portioning scales and stuff like that, each family has its own means. Sharps containers and such, each family has its own.

Telephone communication within the parental treatment team. Telephone communication between parents was also an important factor to the development of the

parental treatment team. During follow-up interviews, the teamwork and trust built through telephone communication resonated strongly with the fathers. Communication by phone played two positive roles for the fathers. First, it was a way for fathers to stay actively involved in treatment even while at work. It also was a way for them to stay abreast of what was happening at home so they could know what to do when they returned, and feel reassured that everything was running smoothly. As Father #1 stated, “When I’m not here we talk on the phone every evening, so we always touch base. I always know what usually happens at home, so even when I’m at work, I know what’s going on.” When fathers did not regularly communicate with their children’s mothers while they were at work, it usually coincided with lower degrees of involvement (i.e., being “not involved” or a “helper”), although not all “helpers” lacked regular phone communication.

In addition to the “primary caregiver” and “equal partner” mentioned earlier who frequently communicated with their children’s mothers to determine appropriate insulin dosages, other fathers referred to how telephone communication helped them stay involved in other ways. Father #6 described telephone communication with his wife as important for him being better able to determine what his daughter needed when he returned home. He stated that “We check that every day at noon anyway to find out how the numbers looked that morning and if I need to change anything at night when I give her insulin.”

On the other hand, some telephone communication was needed only in the case of an emergency, such as a hyper- or hypoglycemic episode. This pattern of communication is more common when the mother is the primary caregiver and father’s involvement in

treatment was sporadic: “We communicate as much as is necessary. If there’s no issue, there’s nothing we discuss. If his blood sugar spikes or drops low, she’ll call and we’ll figure out what to do together.”

Gender role norms and beliefs. There was also evidence that gender role norms and beliefs played a significant role in the development of the treatment team for some fathers. Although some fathers did not mention their beliefs about gender roles, nor were there other indications of their beliefs. These fathers either lacked awareness of gender issues or gender did not hold a prominent place in their minds when relating their experiences with treatment. However, some of the fathers displayed stronger awareness of gender norms and their own beliefs.

One of the fathers (#11) seemed to hold more egalitarian beliefs, and those beliefs resulted in a more egalitarian division of labor in treatment.

I think whenever I was raised, there was a very distinct the husband goes to work and the wife takes care of the kids. That’s probably the way she was raised too. But for us, that’s not the case. We’re a family unit and we all do a little of everything. I may mow the lawn, which she rarely does, but that’s because I enjoy mowing the lawn. I remember when our daughter had one of those ear infections, and her pediatrician had a morning session. I remember me taking her during the week, walking in, looking around and seeing 3 other men with their children. I remember thinking this is kind of neat and quite different from when I was growing up. Thirty years ago, it would have been all mothers. I think we’re more involved in the domestic aspect of the home life than previous generations ... There have been times when one of us has picked up the burden, and then

other times the other one has, but we've been very fortunate with the two of us.

One of us has never been overburdened being the primary caregiver.

Father #9, who changed jobs so that he could have more flexibility for caring for his child, seemed to hold more traditional beliefs, but his behavior reflected a desire to be more involved in treatment.

I had to be strong for my family... I'm a really driven person. I want to do my best and work hard at anything I do. That obviously includes being a father. He's my offspring too; it's not the mother's responsibility, it's both. I have a pretty traditional outlook on marriage.

It seemed that his high level of involvement in treatment and sharing of treatment tasks with his wife was motivated by the desire to be a strong leader for his family, which he saw as traditional, and by his strong work ethic, which spanned multiple roles. For him, being a strong leader meant working hard at everything he did and prioritizing treatment and care over work demands.

For Father #15, his role as a husband and father took on a distinct "breadwinner" flavor, but it did not result in less teamwork. It was apparent from his statements that he saw his primary role as that of a "breadwinner," but his flexibility at work provided him with the leeway to be more involved in treatment than other "breadwinners" might be.

Like I said, it's a team effort. She's always wanted me involved, and I've always been willing to be involved ... I'm head of the household, and it's my responsibility to take care of the family. Primarily that's financial, food, shelter, medical care, and all that. But I'm also the disciplinarian. Jen takes care of them when their sick and mothers them if you will, I hate to use that phrase. She's the

one that picks out their clothes and all that. We each have our own duties, but I'm not an absent father, and she's not an absent mother, so the kids get a lot of attention ... Neither one of us see it as our job and our job alone to do anything with regard to his treatment.

The interaction between gender role beliefs and work flexibility was also present for Father #5, but the interaction worked to the detriment of the teamwork in the parental treatment team. He expressed traditional, breadwinner-oriented gender role beliefs, but also experienced a lack of support from his employers. However, as stated earlier, he recognized that he made the decision to emphasize work over caregiving, and his gender role beliefs played a role in that decision-making. The result of his prioritization of work was that his wife felt that she could not rely on him to be available for caregiving, so she made other caregiving arrangements. He stated that "I'm not really involved in the day-to-day management of our daughter's care. In fact, whenever my wife takes a vacation, she has back-up plans to take care of our daughter."

This case is an example of how fathers' involvement can exist within a recursive relationship with building trust in the parental treatment team. Whereas the continuous involvement of other fathers seemed to encourage more teamwork between parents, this father's lack of involvement encouraged his wife to circumvent the parental treatment team and make other arrangements for their daughter's care. In turn, his wife's arrangements encouraged a further lack of involvement.

In a way it makes me think, "Am I a crappy father? You have to get your mother to come up because I'm not reliable." It helps her treatment, but it provides me with excuses not to be involved. Sometimes I wish my wife would say to me,

“You’re going to be here, and if the job lets you go because you’re here then fine.”

Encouraging child responsibility for treatment and sharing responsibility. One of the processes that most, if not all, families of children with type-1 diabetes experience is encouraging children’s responsibility for their own treatment. Even with young children, but especially as children age and mature, parents are faced with the task of teaching their children to perform treatment tasks on their own so that they can one day be entirely responsible for their own treatment. Several of the fathers (n=5) expressed the need to teach children responsibility for their treatment. As Father #4 stated, “We put a lot of responsibility on her because we could do it for her without her learning, but she’s going to have to do it sooner or later on her own.”

Father #15 connected the need to teach responsibility with the dangers that could result from his child not adhering to treatment regimens:

I got onto him about paying attention and taking care of himself because this is something he’ll have all his life. If he doesn’t pay attention, bad things could happen. But I don’t to be the driving force, because he needs to take care of himself eventually.

Determining the developmental appropriateness of children’s involvement.

Encouraging responsibility seemed to be most closely linked to the questions of when and how much to allow children to be involved in treatment. During the follow-up interviews, the fathers agreed that determining the appropriate amount of responsibility for children was a central theme of encouraging responsibility. For the fathers in the study this was mostly a matter of considering their children’s age, comfort level with

treatment, and maturity levels. The question of when to begin allowing children to be involved was sometimes easily answered by whether their children wanted to be involved in certain treatment tasks. Some young children were more resistant to treatment tasks.

Well, for finger pricks we say “We’ve gotta check you”, and he puts his finger out, no fear, no reservations about that anymore. With shots, it’s kind of become a game. If he sees us getting the syringe ready, he’ll go out and try to hide and say “no shots” and he’ll try to run.

On the other hand, some young children wanted to be involved from an early age. When young children want to perform treatment tasks themselves, parents have to make decisions about which small parts of treatment tasks are appropriate for them to perform and which are not appropriate. For instance, with insulin injections, the fathers of young children were reluctant to allow them to draw insulin from the vial because of the danger of air bubbles and drawing out too much or too little insulin, but they were willing to allow their children to rub the alcohol pad on the injection site or insert the needle and push in the plunger. As Father #6 stated about his six-year-old, “She thought she wanted to try it, and we worked with her. We don’t let her draw the insulin, but we let her do the injection, and make sure she does that right.”

Fathers expected children in middle childhood to take responsibility for entire treatment tasks. Children’s first full responsibility often was for glucose monitoring and entering their readings into a logbook. Many children still did not like giving themselves shots, or did not like to rotate their injection sites, so fathers were still involved in giving their children insulin injections. However, their role shifted from full involvement into

more of a helper role for insulin injections. One father reported how his daughter would give herself shots in the arm, but he would have to give shots in the belly and hip.

As their children took responsibility for glucose monitoring, the fathers also began to shift their role into that of a treatment monitor. Some of the children adhered to their glucose monitoring schedule closely and tracked it in their logbooks, so monitoring was easy for the fathers; all they had to do was check the logbook periodically and occasionally remind their children to check their blood glucose. However, two of the fathers reported that they encountered difficulties with their children failing to monitor their blood glucose on schedule, and then lying to them about having done so. These fathers felt the need to monitor their children more closely as a result.

He checks his own blood sugar and tells us what it is. Of course that can be a problem sometimes. Sometimes he doesn't want to check it and he'll just fib. He doesn't like the finger pokes; it just bothers him ... He will tend to sometimes just straight out lie about it; he'll make up a number and then if I go check out his meter and it's not in its memory, then he admits to it.

The fathers of some teenagers (n=10) encountered other difficulties and successes. Most of the fathers of teenagers reported that their children were almost fully responsible for their treatment tasks, and that their primary job was to monitor their children's treatment. Father #14 even reported that he and his wife had decided that their daughter was mature enough to attend her physician appointments by herself. They sat in the lobby and only went in to appointments when the doctor needed to discuss a change in treatment regimens with them. Only two fathers had teenagers who were not at least mostly responsible for their own treatment.

The difficulties the fathers experienced in monitoring their teenagers' treatment came in two forms: Resistance to their attempts to monitor, and laxness on their own part. The fathers reported that their children did not like it when they attempted to remind them about glucose monitoring and insulin injections. However, this did not seem to faze them, particularly Father #1, and they continued to monitor their children's treatment.

There's a point there where you have to let her do it, and she does pretty much, but as a parent you still have to try to look and she gets irritated every time we ask her, "Did you do your shot? What was your blood today?" You know kids are kids; it doesn't matter if they have diabetes or not, they feel frustrated when parents ask them questions, so that's part of it, but now it's just a routine thing. You just continue on and make sure she gets what she needs. I mean that's our job I think is to bug her and give her a hard time.

As their children gained responsibility for more treatment tasks such as maintaining the logbook, several of the fathers (n=4) reported that they backed off and became more relaxed in their treatment monitoring. Whereas they once checked the logbook more frequently, they began to check it less often. Father #4 reported that he and his wife check the logbook the week before each appointment, and filled in any gaps where there were missing glucose readings (i.e., their insulin pump keeps its own log).

Well, you tend to think the pump's better, so you kind of slack off on checking because when she did shots she was on more of a schedule with us. Now she does it more for herself and we tend to back off. Of course, her being a kid, that's a lot of responsibility for a kid, but we let it slide.

Insulin pumps were an aspect of encouraging children's responsibility for treatment for other reasons, too.

He started taking over his own treatment a year or so before we got the pump. I think that's another reason we decided to get the pump; we started to see where he was becoming more responsible and taking care of himself.

HbA1c (metabolic control) and paternal monitoring. Some of the fathers (n=6) reported on how their children's HbA1c numbers were connected to their involvement in monitoring. The HbA1c (i.e., glycosylated hemoglobin) test is run at each regular physician appointment the children attend. The test determines the level of extra HbA1c in the blood stream, which is an indicator of the average blood glucose control over a period of two or three months. Normal blood glucose levels do not produce much HbA1c, so a low number is the goal. When the HbA1c number is increasing, that means overall metabolic control has not been as good. This tends to provoke anxiety in parents who are attempting to encourage their children's responsibility for treatment. As one father stated, "His A1C has been a little higher than we would like it to be, and that's been something that is a little more worrisome lately."

All six of the fathers who reported on HbA1c numbers were fathers of pre-teens or teenagers. This is significant because it is during the teenage years that metabolic control tends to be the worst (Palmer et al., 2009). The decrease in metabolic control tends to be due to children's desires to be more autonomous before they are ready, and resulting poor treatment adherence. When asked to what he attributed his daughter's increase in HbA1c readings, Father #14 stated that, "Part of it is her kind of feeling her

oats and wanting to do everything herself. Wanting to be independent and not wanting us hovering over her all the time.”

For these fathers, higher HbA1c numbers motivated them to increase their monitoring in an attempt to discover the cause and bring it back under control.

At first we thought he was snacking at night, sneaking something, and he assured us he wasn't. We kept trying to catch him at it, but we couldn't. Obviously it was way past time to make an adjustment ... If his numbers seem to be getting high, we really start paying more attention to what he eats, his blood levels, shots, his physical activity. When he plays football we have to give him snacks because he burns more carbs, but in the winter, we have to watch the numbers closely. We may make him go outside and play in the cold. We may even wrestle in the living room.

Even Father #5, the father who was “not involved” in treatment, felt motivated to increase his monitoring when his daughter's HbA1c numbers were increasing. However, his attempts to help her regain metabolic control were derailed by other parenting problems, which he said were an over-compensation for his lack of involvement.

I tend to be goal-oriented, so if we want the A1C at 8, and we're at 9.3, how do I get from 9.3 to 8. They tend to be more emotional about it, “Well, it's not that easy!” But I'm wondering how do you get there. So I've tried different things, different contests. But I also spoil Madison, very much.

Divorce, separation, remarriage, and children's responsibility for treatment. The quality of the coparenting relationship between divorced or separated parents was not only important to the formation of the parental treatment team, but to how well parents

were able to encourage their children's responsibility for treatment. The juxtaposition of the experiences of two of the fathers provides a good example of the importance of the coparenting relationship to encouraging children's responsibility.

One of the fathers, Father #7, who was in the middle of a highly adversarial divorce, reported how he had difficulty helping his daughter become more responsible for her diet and glucose monitoring because he and his ex-wife were not enforcing the same rules about treatment and diet. For instance, he had trouble cooperating with his ex-wife about using the logbook correctly to track blood glucose and insulin dosages. He also reported at another point in the interview that he did not hear from his children when they were at their mother's house and when he encountered them one time while they were out with their mother, both were disrespectful to him in front of their mother and she ignored it.

Well the guardian ad litem said they want her to start getting more independent in doing that, so that's what I've been trying to do. But when I try to get my daughter to do it, I get defiance. If I ask her to check her blood sugar, she says she's going to do it, but she doesn't ... then it got to the point where she was eating whatever she wanted when she was over there, and she started spinning out of control.

On the other hand, Father #10 reported on how his cooperative relationship with his ex-partner was helpful to encouraging his son's responsibility for treatment.

You don't see that type of interaction a lot. It's all about Cameron, it's all about how he's taking care of it. It's beyond anything I see from folks that are in these types of situations with blended families. I mean, typically someone has

something poorly to say about one another, but we're just not that way... Each family had a different take on it of how they were going to do it, but the end result was still the same.

It seemed from the data from these two fathers that when separated parents cooperated with one another and place their child's needs first, the child learned responsibility because he had parents who presented a unified front and there was little leeway for poor treatment management. In addition, when parents "got along" there was likely to be less fighting about differences in treatment management and monitoring, so the child was not able to use one parent against the other. When parents were not cooperative coparents, however, their child was more likely to manage treatment poorly because they did not have basically the same rules in both households and one parent may have been more likely to engender defiance in their child.

How Do Fathers Want to be More Involved in Treatment?

Some of the fathers described wanting to be more involved in general, wanting to be more involved in certain treatment tasks, and to attend more appointments. For instance, Father #5 reported that he knew his wife wanted him to be more involved in treatment, but he did not know how to be more involved because of work.

How I'd like to be more involved is I need to make more of a commitment to be at these appointments. Look at today. I come up here and the minute we're supposed to walk up here I have to take a call, and I miss the entire visit. That sends the wrong message to my child. It sends the wrong message about what's important.

Two fathers (#8 and #12) described wanting to be more involved in certain tasks (e.g., changing children's injection sites), but did not feel confident in doing so; they felt that they lacked the knowledge and skills necessary to perform these tasks.

Whenever they started doing the pump, I learned some about it, but really my wife and her mom are the ones who take care of it. If we have trouble with a pump, or need to change an injection site, she handles it. I have a fear of tearing it up or doing it wrong. The last two times I changed one, the first one I put on each time was bad. It wouldn't take the insulin.

Father #8 at first stated that he had been trained to change injection sites and that his lack of involvement in changing injection sites was due to needing to take care of their other daughter while it was being done, but later in the interview he stated that he did not feel comfortable with doing it, and he would like to gain skills in doing so. It is possible that his lack of skills was tied to falling out of practice in changing the sites.

I'm just not comfortable with changing the injection sites. I think I'm comfortable with everything else. That's just the major piece of the puzzle I'm not really involved in.

These fathers, who were less involved in treatment than many of the others, felt that their involvement could be increased by gaining more knowledge of how to perform certain treatment tasks. On the other hand, even those who were the most involved in treatment thought that they would like to gain more knowledge as well. Father #3, an "equal partner" who essentially was a primary caregiver while his wife was traveling for work, stated that he would like to gain more specific knowledge of proper nutrition for his daughter so he could cook better meals for her metabolic control.

There's a lot more I could learn, and more on the diet side. I've tried to find someone familiar with diabetes to give me some good ideas. Columbia has a dietician up there, but they're not here. I know I can call them, but that's easier said than done sometimes. The girl at Hy-Vee was helpful about what to look for on the store shelves. That's where I'm frustrated, how do you expand and create new dishes that meet the requirements, but are also tasty and she'll like that we can cook. So I feel like I can always improve.

Father #6 reported that he would like to gain more knowledge in how to calculate the dosages of insulin his daughter needed based on glucose readings, carbohydrate intake, and exercise.

That's probably the main thing that hampers me - the numbers. I know she's read a lot of diabetes books. I probably need to read those. That would probably be a good way for me to get better at it, but I haven't really taken the time to do that. I think it'd be helpful to have a couple of refresher course. When we did it the first time, it was kind of overwhelming. It'd be nice to take another class, more study, maybe even a 1 day class to review. There are some things I've forgotten, or maybe just haven't had to deal with because she does it ... If I were more knowledgeable, I would not have to call her as much and give her more of a break (Laughs). She could get out and go see her mom for a week and get totally away from it.

This collection of statements tied several factors together. First, this father recognized that he needed to take the initiative to gain more knowledge by reading more books and training materials. In addition, he also acknowledged that he once learned the

skills he needed, but has not had to use them because his wife took care of most of the calculations. Finally, he suggested the need for refresher courses, possibly put together by the same team that initially trained him and his wife.

Chapter Four

Discussion

The purpose of this study was to generate a theoretical model of influences on paternal involvement in the treatment and care of children with type-1 diabetes. This was accomplished by interviewing 15 fathers of children with type-1 diabetes to identify key concepts of paternal involvement and the conditions that influenced it and to describe the relationships between those conditions in the form of processes the families experienced. Fathers in the study described macro- and micro-level conditions that interacted to inform various family processes (i.e., *navigating the emotional waters, balancing work and family demands, building trust within the parental treatment team, and encouraging child responsibility*). These family processes influenced the formation of a key treatment process, *sharing the responsibilities* of treatment and care, which was connected to how and to what extent fathers were involved in treatment and care. In addition, fathers' involvement in treatment fed back into the family process of building trust within the parental treatment team, which informed future paternal involvement.

The research questions (i.e., “How are fathers involved in treatment and care of their children with type 1 diabetes?” and “What influences paternal involvement in treatment and care?”) were answered within the processes present in the model. Both around the time of their children's diagnosis and over time as they settled into their treatment roles, fathers had to manage their own fears and anxieties, and that of their family members, about their children's illness and treatment. The fear and anxiety they experienced affected how they initially set up their treatment routines, and how they encouraged their children's responsibility and involvement in treatment.

In balancing their work and family demands, the key factor was how fathers prioritized their children's treatment needs in relation to their other work and family demands. When fathers perceived power in their decision-making, in addition to flexibility at work, supportiveness from their employers, and holding more egalitarian gender role beliefs, they tended to be more involved in treatment than were fathers who experienced lack of flexibility in work hours, little support from employers, and more traditional gender beliefs. In addition, it is important to note that fathers' decision-making about their work-family priorities happened within the context of their families' overall adaptability and strategies for encountering family stress. Some families were more apt to develop new strategies for coping with their children's treatment needs (e.g., changing work roles and environments to allow for flexibility in caregiving), while others maintained similar patterns as were present before their children were diagnosed (e.g., continuing to be a "workaholic").

In the process of building trust within the parental treatment team, the fathers' real and perceived knowledge of diabetes and treatment tasks seemed to be the most important factor. When fathers did not perceive that they were skillful and knowledgeable in their children's treatment tasks, then their children's mothers tended to be the primary caregivers. This was either because they did not trust their husbands to be able to perform treatment tasks or they "took over" treatment. When fathers perceived higher levels of skills and knowledge, they tended to be more involved in treatment and developed a high level of trust with their children's mothers, except in cases where the mothers lack competence. In these cases, fathers took on more responsibility for treatment tasks than their children's mothers.

As the fathers encouraged their children's responsibility for treatment, the primary challenge they faced was deciding how much responsibility was appropriate for their children. As fathers gave their children more responsibility, and their children became more involved in treatment, fathers' direct involvement in care decreased, and their monitoring of treatment increased. They increased their monitoring even more in times of distress brought on by poor metabolic control.

Finally, some of the fathers expressed ways they could be more involved in treatment. Some of them reported wanting to be more involved in general, and others conveyed that they wanted to be more involved in certain tasks. There was also a strong recognition that they would be more involved in treatment if they knew more about treatment tasks and felt more competent in performing them. Their knowledge about diabetes and treatment was partially influenced by their initiative to learn, but also a matter of maintaining their skills through practice.

The Findings in the Context of Previous Theory and Research

Lamb et al. (1985) and Pleck and Masciadrelli (2004) proposed a four-factor model of the sources of influence on father involvement. The model included: 1) motivation, 2) skills and self-confidence, 3) social support, and 4) institutional barriers. The overall model of influences on paternal involvement in treatment and care of children with T1D reflected these factors. In addition, the model suggested the existence of some interactions between the factors in the four-factor model. Finally, based on the data from this study, another factor regarding changes in children's responsibility for treatment could be considered in addition to the four-factor model for fathers of children with T1D.

Motivations for paternal involvement. The fathers in this study appeared to draw some motivation for treatment engagement from their families' emotional context. The fathers commonly described anxiety and guilt. These emotions were consistent with past research on family adjustment to diabetes diagnosis and treatment (Sullivan-Bolyai, 2002, 2003; Landolt et al., 2002). In these studies, parents of children with T1D experienced heightened levels of stress during the time of diagnosis, because of the difficulties associated with treatment management, and because of worries over diabetes complications.

Fathers who described their own experiences of intense emotion during the time of their children's diagnosis seemed to be more emotionally engaged in treatment than fathers who did not describe their emotions. Fathers who did not describe intense emotions for themselves sometimes ascribed all such feelings to their child's mother; they stated that their children's mothers were more emotional than they were about their children's illness and treatment. These fathers also seemed to be reflecting gender beliefs (i.e., mothers are naturally more emotional) within these statements. Such gender beliefs are important because they also have been found to provide motivation or de-motivation for involvement in parenting for fathers (Pleck, 2012). Fathers might justify disengagement to themselves when they believe that mothers are naturally more emotional and, therefore, naturally more engaged in treatment than fathers have to be.

In addition, the feelings of fear and uncertainty fathers experienced motivated some fathers to maintain contact with their children's treatment team in the first few weeks after diagnoses; this contact seemed to have a calming and stabilizing influence on

the families. Such contact may be important to ongoing educational efforts for families of children with newly diagnosed type-1 diabetes.

Finally, the anxiety fathers experienced also influenced how they encouraged their children's responsibility for treatment. While fathers were deciding what treatment tasks were developmentally appropriate for their children, they experienced anxiety about their children hurting themselves or performing treatment tasks incorrectly; this informed their choices about what tasks to allow their children to perform.

There have been mixed findings in past research on how children's gender is connected to father involvement. Marsiglio (1991) found that fathers were more engaged with male children than female children, but Hofferth (2003) found that child gender was unrelated to paternal engagement. Pleck and Masciadrelli (2004), in reviewing these and similar findings, proposed that child gender may have less of an impact on involvement currently than it did in previous decades. In the current study, there seemed to be no indication of fathers being more engaged with male children than with female children, either in direct treatment tasks or in monitoring children's treatment. It was possible that Pleck and Masciadrelli (2004) were correct that child gender is less impactful than it used to be, but it was also possible that children's treatment needs overrode any fathers' tendencies to be more engaged in care for boys than they would be for girls, at least for this sample of mostly involved fathers.

Finally, the fathers' descriptions of their parenting involvement and daily lives before diagnosis were typical of father's reports of their interactions with their children in that their interactions emphasized play and leisure activities (Russell & Saebel, 1997). In addition, a comparison between the fathers' descriptions of their pre-diagnosis and post-

diagnosis involvement revealed that fathers who were involved before their children's diagnosis (i.e., whether through play or activity involvement, or generally spending time with their children) tended to be more involved in treatment than were fathers who described themselves as "workaholics" or did not provide much description of their pre-diagnosis involvement.

Furthermore, some of the fathers seemed to find it significant that they were no longer able to engage in leisure activities "at will" due to their children's treatment needs. Although these fathers remained involved in treatment either directly or as treatment monitors, as did most of the sample, such a change in lifestyle could provide motivation for some fathers who were unlikely to be involved in treatment to disengage from it. It would be interesting to see if this were a factor for a larger sample of fathers who were not involved in their children's treatment.

Connection between motivations and institutional barriers. The process of balancing work and family demands was the most salient influence on how the families shared the responsibility for treatment and how much fathers were involved in treatment. It also may have provided some clues about connections between motivational factors such as gender role beliefs and institutional barriers to father involvement.

Fathers reported that their families' daily treatment routines at home were balanced with their work schedules, activity schedules, household labor, other children's care needs, and sleep schedules. Of paramount importance in this balance was how the fathers prioritized various work and family demands. Fathers who were more involved in their children's treatment tended to prioritize their children's treatment over work demands whenever possible, while fathers who were less involved were more likely to

have decided at some point to prioritize work over treatment. This finding aligns well with Pleck's (2010) assertion that fathers are not necessarily passive in how their work demands influence their involvement in parenting. Fathers often have the ability to make decisions about their work demands, although there could be variation between job types. Fathers in white-collar, salaried jobs may have more decision-making power than fathers in blue-collar, hourly-pay jobs. Socioeconomic status could be influential here as well. Fathers who earn small incomes may be less inclined to take time off from work to care for a sick child or to attend a physician appointment because they lose income when they do so, and they may be in danger of losing their jobs. Fathers with higher incomes may feel more financially able to be involved.

In addition, the fathers who prioritized work over treatment and caregiving demands tended to display gender role beliefs that were more oriented to breadwinning than caregiving. On the other hand, fathers who were aware of gender norms of "new fatherhood" and held more egalitarian gender role beliefs were more likely to prioritize treatment and caregiving demands over work. Gender role beliefs seemed to provide motivation (Pleck, 2012) for fathers' decision-making and involvement in treatment.

Another factor that may be tied to fathers' perceptions of their power in decision-making is their children's mothers' employment status. Hall (1994) found that fathers whose partners were employed were more engaged in caregiving activities with their children than were fathers with partners who stayed-at-home. There was not a definable pattern in the data from the current study regarding a connection between fathers' involvement and mothers' employment status. Some fathers whose partners stayed at home were more involved in treatment than were some fathers whose partners worked

full-time. However, the employment status of their children's mothers appeared to be connected to the decision-making in which fathers engaged regarding the balance of work and family demands. When mothers were employed outside the home, fathers did not seem to perceive the same pressure to maintain employment as did fathers whose wives were stay-at-home mothers. When fathers perceived pressure to maintain employment, they also seemed to perceive less decision-making power.

One curious phenomenon occurred in fathers' explanations about how their families' developed their treatment routines. When fathers were describing their daily routines, one of the questions I asked to reveal information about how and why the routines developed was "How did you and your wife/family negotiate or discuss who was going to perform what tasks and when?" When I asked this question to several fathers, their answer was that there was no negotiation or discussion; it "just happened" based on "what was easiest" for the family. It is possible that the fathers simply did not recall any direct negotiations or discussions. Their lack of recall could be because mothers tend to be primary care managers for their children (Seiffge-Krenke 2001, 2002), and mothers would be more aware of such negotiations and discussions than would fathers. However, it is also possible that the fathers' recall was accurate, and no discussions or direct negotiations ever took place. Lederer and Jackson (1968), in some early work on communication and family systems theory, asserted that families' rules and roles often evolve outside of their conscious awareness. It would be interesting in future research to see if mothers recall never having negotiated or discussed their treatment roles.

Connections between social support and fathers' skills and self-confidence.

The process of building trust in the parental treatment team may have provided some

information about connections between social support and fathers' skills and self-confidence. According to Pleck (2012), the most important social support for fathers' involvement comes from their children's mothers in two forms: The mothers' own involvement and their encouragement of fathers' involvement. Mothers' high involvement in caregiving has been associated with fathers being more involved in treatment, possibly because fathers felt guilty and did not want to place all the burden of caregiving on their children's mothers (Pleck & Hofferth, 2008). In addition, mothers' encouragement of fathers' involvement in caregiving has been connected to higher paternal involvement, whereas maternal gatekeeping behaviors have been connected to lower paternal involvement (Schoppe-Sullivan et al., 2008).

In the current study, fathers' knowledge, perceptions of competence, and self-efficacy (self-confidence) in performing treatment tasks may have been important to how mothers' own involvement and their encouragement of fathers' involvement were connected to the extent of fathers' involvement in treatment. Fathers who perceived their own poor knowledge about treatment and did not feel confident in performing treatment tasks were less likely to be involved in treatment. These fathers also were more likely to cede treatment management to their children's mothers. When fathers displayed high self-efficacy and perceived that they had a high degree of knowledge about treatment, they were more likely to be involved in treatment tasks and management. The mothers, however, did not decrease their own involvement in response to fathers who were more involved (Pleck and Hofferth, 2008); they just did not discourage fathers or take over treatment (i.e., hallmarks of maternal gatekeeping).

On the other hand, fathers' lack of knowledge or competence in treatment tasks may encourage maternal gatekeeping. Mothers' gatekeeping sometimes takes the form of chastising fathers for mistakes they make in caregiving (Schoppe-Sullivan et al., 2008). Considering the high stakes involved in mistakes while performing treatment tasks for children with T1D (Buckloh et al., 2008), mothers may be even more likely to chastise fathers when they observe mistakes. This type of gatekeeping is likely to discourage paternal involvement in caregiving, which could encourage more maternal gatekeeping in the form of mothers taking over treatment.

Children's responsibility for treatment as a source of paternal involvement in treatment. One potential source of paternal involvement in treatment revealed in this study that was not addressed in the four-factor model presented by Lamb et al. (1985) and Pleck & Masciadrelli (2004) was children's own responsibility for treatment. The four-factor model did not address this factor because it considered paternal involvement in parenting in general, but children's responsibility for treatment could be comparable to other forms of responsibility and autonomy that children display over time.

In the current study, when children began to take over treatment tasks, fathers' direct involvement in care decreased and their monitoring of children's treatment increased. However, as their children became more responsible for treatment as a whole, fathers' monitoring tended to decrease as they became more confident in their children's ability to handle treatment responsibly. In addition, when there was a prolonged pattern of high HbA1c numbers, fathers' increased their monitoring so they could find the reason and fix it.

Limitations

The study suffered from two primary limitations. First, the sample was comprised entirely of middle-class fathers, and only one of the fathers was Black. All of the fathers in the study worked full-time, and mostly in white-collar jobs (i.e., there were three “blue collar” workers and only one of them worked for hourly pay). Secondly, almost all of the fathers were at least somewhat involved in the treatment and care of their children. There was only one who was considered to be “not involved.”

Having only middle-class fathers in the sample was a drawback because middle-class fathers may be different from fathers in lower-income families, particularly regarding their access to health care resources and the decision-making in which they can engage about balancing their work and family demands. Lower-income families’ access to health care resources is limited by the struggles they experience in obtaining medical coverage and medical supplies (Tamis-Lemonda & McFadden, 2010). The statements made by some of the fathers in this study regarding health insurance and job security (i.e., pressure to work long hours so that they could continue in their jobs and keep insurance) may not be part of the reality for low-income fathers whose jobs do not provide health insurance in the first place. Only one of the fathers in this study worked in conditions that mildly reflected those of lower-income fathers; he was a blue-collar worker who worked on hourly pay, so his flexibility to leave work to go to appointments or care for a sick child was virtually non-existent.

In addition, having only middle-class fathers in the sample may have skewed the findings regarding how fathers were involved in treatment in relation to the equipment available to them. Lower income families may not have access to reliable glucose meters

and insulin pumps. They may rely on other methods for knowing their children's blood glucose levels that are less reliable, such as being aware of feelings of weakness or fatigue. Such methods may result in poor metabolic control. In addition, when lower income families' medical coverage does not allow access to insulin pumps, the ability to maintain adequate metabolic control may be impaired because they cannot be accurate enough with insulin dosages (i.e., insulin pumps measure to a fraction of a unit, whereas insulin syringes measure insulin by the unit), especially in young children, who need smaller doses of insulin. Because poor metabolic control seems to be tied to fathers' involvement through increased monitoring, particularly for adolescents (Palmer et al., 2009), lower income fathers' involvement in relation to metabolic control also may be different than it was for fathers in this sample.

Fathers who engaged in lower levels of involvement than others were particularly difficult to access for this study for several reasons. For one, they were less likely to be in attendance at their children's appointments, so they could not be recruited face-to-face. The one father in the study who was "not involved" just happened to be at his child's appointment that day, walked in at the end of the appointment, and was willing to be interviewed for the study on the spot. In addition, when fathers were not in attendance at the appointment, their children's mothers controlled access to them to some degree. When only the mothers were present, I had to rely on them to bring the study information to their children's fathers. Most mothers provided me with contact information for the fathers, but two of them refused to provide contact information outright. Even when I called fathers after obtaining their contact information, many (n=23) did not answer or return phone calls, and 10 refused to participate. Although I was unable to collect data

from these fathers, it is possible that many of them were less involved in treatment than most of the fathers who chose to participate.

The presence of very few less-involved fathers, and only one who was not involved in treatment, may have resulted in different findings for this study than would have been found with a larger proportion of less-involved or not-involved fathers in the sample. Although some of them were able to contribute reasons why they were less involved than others (i.e., primarily lack of work flexibility, decision-making, knowledge, self-confidence, and highly involved mothers), the data on what hindered less-involved fathers' involvement may have been more rich had more of them been in the sample. On the other hand, even with more fathers with lower involvement than others in the sample, the data may not have gained much depth because such fathers may be less insightful about the reasons behind their lack of involvement or more reluctant to discuss them.

In addition, using both telephone interviews and face-to-face interviews likely influenced the way the interviews with fathers unfolded. In face-to-face interviews, it was easier to be aware of the fathers' emotional cues within their stories and, in response, probe more deeply into their experiences. During telephone interviews, such awareness and probing was more difficult. There were also more interruptions during telephone interviews due to phone reception and environmental distractions (e.g., one father was in a noisy room and watching TV during the beginning of an interview); the face-to-face interviews occurred in exam rooms and conference rooms. The interruptions during telephone interviews made it difficult to track the conversations with the fathers, particularly when reception was lost.

Research Implications

Several research questions and routes for further investigation were derived from the findings and limitations of the current study. Researchers who conduct future research on the factors that influence fathers' involvement in treatment and care of children with T1D could attempt to further test the connections between father's internal motivations for involvement (e.g., emotions and gender role beliefs), and the way they make decisions regarding how to balance or prioritize treatment demands with other family and work demands. One factor to consider in conjunction with such investigations is workplace policies about family and medical leave. How do fathers make decisions to access their available leave benefits when their children are sick or need to attend a physician's appointment? How do variations in workplace policy affect father's decision-making?

Another question to consider is how fathers and mothers make decisions about the developmental appropriateness of their children engaging in treatment tasks over time and across child age. Some research has been performed on how parents encourage age-appropriate autonomy in adolescent children (Palmer et al., 2009; Seiffge-Krenke, 2002; Weibe et al., 2008), usually through monitoring their children's treatment adherence. However, the research on how parents encourage responsibility in younger children has been virtually non-existent, although some research has shown that young children often try to "help" with treatment tasks by performing small tasks associated with injections and glucose monitoring (e.g., pushing in the plunger; Savinetti-Rose, 1994). In the current study, there was evidence that fathers and mothers allow their young children to

perform small tasks they consider developmentally appropriate based on age and maturity levels, but further development of this topic is needed.

Finally, one question was derived from data not discussed in this report. One of the fathers reported at length on the adversarial interactions he had with his child's school surrounding her diabetes and treatment, particularly regarding what he considered to be poor decisions they were making about her educational plan and grades immediately following her diagnosis. This father reported that he thought it was his duty to "fight for" his daughter in interactions with the school. One of the other fathers reported that he thought parents should not treat schools as though they owe diabetic children special consideration, and that it is the parents' job to make sure their children succeed and have all the resources they need at school. The differences between these two fathers' perspectives could prompt further investigations into the interactions between parents and their children's schools regarding diabetes and treatment. Such studies would be particularly interesting to conduct with fathers because of the possibility for more paternal intervention on the part of female children than male children because of some fathers' gender role-driven motivations to protect daughters and encourage autonomy in sons (Pleck & Masciadrelli, 2004).

Implications for Practice

The primary implications of this study for family medical practitioners exist in how they can encourage more paternal involvement. Efforts to encourage paternal involvement should account for several factors. First, many fathers need more knowledge of diabetes and treatment. The attainment of this knowledge depends on its accessibility (e.g., books, take-home training materials, extra training in the form of

classes), and fathers' initiative in accessing those resources. Fathers attending children's appointments may be important to these educational efforts because doing so allows them to hear first-hand what is occurring in their child's illness and treatment, and it provides an opportunity for them to ask questions about treatment tasks. Physicians, nurses, and nutritionists should be conscious of providing such opportunities during appointments.

However, because of work schedules and other barriers, fathers cannot always attend appointments. If it is less than feasible for treatment teams to schedule evening and weekend appointments to accommodate fathers' schedules, treatment teams should consider ways to provide other opportunities for education. This occurs quite often in the form of pamphlets that families receive at their appointments, and in the educational materials families take home with them after their initial training during their children's hospitalization. In addition to these passive efforts, treatment teams should consider creating follow-up educational sessions, which could take place in families' homes. Such sessions also should be scheduled for times when fathers most typically would be home from work.

These follow-up sessions are important because the initial training at the time of their children's hospitalization can be overwhelming to families and they may be more likely to forget the information they learned, particularly fathers who are out-of-practice because their children's mothers take on most of the treatment responsibility (Hackett, 1989) or those who do not regularly attend appointments. In addition, there is evidence that learning does not easily transfer from one context to another (Barnett & Ceci, 2002). Educational efforts about diabetes and treatment that take place within the context in

which the learning most often will be applied (e.g., families' homes) may result in more retention and application of knowledge for fathers.

Finally, when appropriate (i.e., when fathers are at least somewhat involved and mothers want them to be involved in treatment), members of the medical treatment team should encourage mothers to create space for fathers to be more involved in treatment. This can be accomplished by mothers making a conscious effort to involve fathers in treatment tasks, even training them at home, and by attempting to not chastise fathers when they perform a task incorrectly. Doing so will allow fathers to practice their skills in an encouraging environment, which will help them retain knowledge and skills over the long-term and maintain higher levels of involvement in treatment.

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Appendix A

Dear Father and Potential Research Participant,

You are invited to participate in a study about father involvement in the treatment and care of children with type-1 diabetes. This study is being conducted by Shaun Calix and Lawrence Ganong from the Department of Human Development and Family Studies at the University of Missouri. You were selected as a possible participant because your child is treated in the endocrinology clinic of the University Children's Hospital.

Whether you are your child's biological father or stepfather, your participation is very important to us. We do not know enough about how fathers of children with diabetes are involved in their care and treatment. Nor do we know enough about factors that influence fathers' involvement. In this study, we hope to interview fathers to help us gain an understanding of their involvement and of what helps and hinders their involvement.

If you are interested in participating in this study or you want more information, you may call me (Shaun Calix) at 314-397-2021 or send an email to sic4gb@mail.missouri.edu. You may also provide your email address to Danita Rife in the Pediatric and Adolescent Specialty Clinic. If you email me, please provide a telephone number or email address at which I can contact you. Should you choose to participate, I will call you to conduct an approximately 30 minute interview, either face-to-face or via telephone (the option belongs to you). In addition, if you give your consent, I may call you or meet with you to conduct a brief follow-up interview.

More detailed information about study procedures can be found in the enclosed study consent form.

Thank you for considering this opportunity to contribute to my understanding of fathers of children with diabetes. I look forward to hearing from you.

Respectfully,

Shaun Calix
Doctoral Candidate
Department of Human Development and Family Studies
University of Missouri

Appendix B

Dear Mother of a Child with Diabetes,

I am a graduate student in the Department of Human Development and Family Studies at the University of Missouri. I am conducting a study about father involvement in the treatment and care of children with type-1 diabetes. I hope to learn more about how fathers are involved in the treatment and care of children with chronic illnesses, and what helps or hinders their involvement.

I need your help in recruiting the biological father and/or stepfather of your child with diabetes for participation in my study. If you received the packet that contains this letter at your child's physician appointment, please pass the packet and letters on to your child's father or stepfathers. If both a biological and stepfather are involved in your child's life, please pass on the letter to fathers to **both** the biological father and stepfather (there should be two in the packet).

Because I will be interviewing fathers, your own participation in the study will not be necessary; however, your help in making sure your child's father and/or stepfather knows about the study will be greatly appreciated.

Thank you in advance for your assistance!

Respectfully,

Shaun Calix
Doctoral Candidate
Department of Human Development and Family Studies
University of Missouri

Appendix C

Consent Form to Participate in a Research Study

INVESTIGATOR'S NAME: SHAUN CALIX AND DR. LAWRENCE GANONG
PROJECT # 1201025

Study Title: Constructing a Grounded Theory of Influences on Paternal Involvement in the Treatment and Care of Children with Type-1 Diabetes

Introduction

This consent may contain words that you do not understand. Please ask the investigator or the study staff to explain any words or information that you do not clearly understand.

This is a research study. Research studies include only people who choose to participate. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

Please take your time to make your decision and discuss it with your family and friends.

You are being asked to take part in this study because you are a biological father or stepfather of a child (age 18 months to 17 years) with type-1 diabetes.

In order to participate in this study, it will be necessary to give your written consent.

Why Is This Study Being Done?

The purpose of this study is to understand how fathers are involved in the treatment and care of children with type-1 diabetes, and what helps or hinders their involvement. This research is being done because we do not know enough about fathers' involvement in the treatment and care of children with type-1 diabetes; knowing more could help health care professionals work more effectively to encourage and educate fathers of children with type-1 diabetes.

How Many People Will Take Part In The Study?

About 20 people will take part in this study in the state of Missouri.

What Is Involved in the Study?

If you take part in this study, you will take part in an approximately 30 minute interview in which you will be asked questions about your experience caring for a child with type-1 diabetes, and factors that help or hinder your involvement with treatment and care. You will also be asked to participate in follow-up interviews as the need arises. The interviews will occur at the clinic where your child goes for appointments, another site, or by telephone depending on your convenience and availability.

How Long Will I Be in the Study?

We think you will be enrolled in the study for several months, but your total time commitment will likely not be more than 90 minutes over the course of the study. If you are willing, we would like to interview you once for 30 minutes, and then ask you to participate in brief follow-up interviews in which we would ask you some different questions or for clarification on previous responses.

You can stop participating at any time. Your decision to withdraw from the study will not affect in any way your medical care and/or benefits. If you decide to stop participating, you may inform the interviewer (Shaun Calix) at any time, either during interviews or by phone or email.

What Are the Risks of the Study?

While in the study, you are at risk for psychological, relational, or social consequences. You should discuss these consequences with the investigator. There may also be other consequences that we cannot predict.

Risks related to the interviews include:

Social and relational consequences

If you reveal your responses to friends or family, they may not like your responses.

Psychological consequences

Answering questions about your relationships or involvement in care could trigger psychological distress.

Legal consequences

The researcher is legally obligated to report any child abuse that could be revealed during an interview.

For the reasons stated above the investigator will observe you closely while interviewing you, and if you have any worrisome symptoms of distress, notify the investigator immediately. Shaun Calix's telephone number is [314-397-2021](tel:314-397-2021). For more information

about risks and side effects, ask the investigator or contact Dr. Lawrence Ganong at 573-882-6852.

Are There Benefits to Taking Part in the Study?

If you agree to take part in this study, there may or may not be direct benefit to you. You may expect to benefit from taking part in this research to the extent that you are contributing to scholarly knowledge. We hope the information learned from this study will benefit other fathers of children with type-1 diabetes in the future.

What Other Options Are There?

An alternative is to not participate in this research study. Please discuss these and other options with the investigator. Remember that your child's eligibility for treatment will not be affected by your decision whether or not to participate in this study.

What about Confidentiality?

Information produced by this study will be stored in the investigator's file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law. If the investigator conducting this study is not your primary or regular doctor, he/she must obtain your permission before contacting your regular doctor for information about your child's past medical history or to inform them that you are in study.

It is possible that your child's medical and/or research record, including sensitive information and/or identifying information, may be inspected and/or copied by the study sponsor (and/or its agent), federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your record is inspected or copied by the study sponsor (and/or its agents), or by any of these agencies, the University of Missouri will use reasonable efforts to protect your privacy and the confidentiality of your medical information.

The results of this study may be published in a medical book or journal or used for teaching purposes. However, your name or other identifying information will not be used in any publication or teaching materials without your specific permission.

The interviews will be audio recorded using a digital voice recorder (DVR). The recordings will be saved to a personal computer and backed up on CD. Both storage spaces will be password protected. Once uploaded and backed up, the DVR audio recordings will be deleted from the DVR.

What Are the Costs?

There is no cost to you for the interview itself. However, you will be paying for the normal cost of transportation and your child's routine medical care.

Please note that added costs may include insurance co-payments for doctor visits, transportation, parking, and/or other possible expenses during your participation in this study. Please discuss these issues with the study investigator and/or your doctor.

Will I be Paid for Participating in the Study?

You will not be paid for your participation in this study.

What Are My Rights as a Participant?

Participation in this study is voluntary. You do not have to participate in this study. Your child's present or future care will not be affected should you choose not to participate. If you decide to participate, you can change your mind and drop out of the study at any time without affecting your child's present or future care in the clinic at which he or she receives care. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. In addition, the investigator of this study may decide to end your participation in this study at any time after he has explained the reasons for doing so and has helped arrange for your continued care by your own doctor, if needed.

Whom Do I Call if I Have Questions or Problems?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Health Sciences Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181.

You may ask more questions about the study at any time. For questions about the study, contact Shaun Calix or Dr. Lawrence Ganong at 314-397-2021 and 573-882-6852.

A copy of this consent form will be given to you to keep.

Sign _____

Date _____

Appendix D

Basic and Supplemental Interview Questions for Initial Interviews

1. Tell me about your experiences in caring for your child with type-I diabetes.
 - a. Describe a typical day in your home. Who does what with the children, around the house?
 - b. In caring for and treating your child with diabetes, who does what and when?
 - c. What kinds of things do you and your child do together?
2. What do you think has helped you be involved in your child's treatment?
3. What do you think hinders you from being involved in your child's treatment?
4. How would you rate your relationship with your child's mother on the following scale: excellent, good, fair, or poor?
 - a. Why did you provide that rating? How do you think she influences your involvement in your child's care?
5. Tell me about other people who help take care of your child.
 - a. How do they, or the presence of their help, influence your involvement?
6. Tell me about work. How does it influence your involvement?
7. How would you rate your knowledge of diabetes and its treatment?
 - a. What, if any, is the connection between your knowledge and involvement?

Appendix E

Additional Interview Questions for Theoretical Sampling

1. How were you involved as a parent before your child's diagnosis?
2. How much flexibility do you have to take time off from work to help out or go to appointments?
3. How did you and your family develop your routine?
 - a. Who was involved in housework while the other helped with treatment?
 - b. Who took care of the other children?
4. How did you monitor your child's treatment adherence?
 - a. How did your children respond to your monitoring attempts?
 - b. Who did more monitoring?
 - c. What is your role now in helping your child maintain metabolic control (A1C)?
 - d. How did you respond to the A1C numbers going up?
5. How is your child involved in his own treatment?
 - a. How has your involvement changed over time?
6. How do you and your wife communicate about treatment while you are at work?
 - a. How much does your wife want you involved in treatment?
7. How well do you and your ex-partner cooperate around your child's treatment?
 - a. How do you keep track of your child's numbers between households?
 - b. How is your ex-partner/ your partner's ex involved in treatment?

Appendix F

Follow-up Interview Basic Questions

1. How did the emotions you experienced surrounding your child's diagnosis influenced the way your family developed its treatment routine?
2. A lot of the fathers talked about having to balance their children's treatment needs with other work and family demands like work and sleep schedules, eating schedules, household chores and taking care of other children. What kind of impact did balancing those demands have on your family's routine and your involvement?
3. Tell me a bit more about how you make decisions about when to take time off from work to take care of your child when he or she is sick?
4. How did you and your child's mother decide what treatment tasks were appropriate for your child to perform?
5. How have you and your child's mother encouraged your child's responsibility for treatment over time?
6. How did you and your child's mother build up trust in one another to perform treatment tasks?
7. How did your knowledge and skills and her knowledge and skills regarding treatment play a role in how you developed trust in one another?
8. One of the other things I've seen is that when fathers are more involved in treatment that helps with the teamwork between parents, and when they are less involved in treatment, the teamwork suffers. What do you think about that?

Appendix G

Representative Quotes for Family Processes

Navigating the emotional watersFather #1

Well anything happens to your child, it's always an emotional thing right off the get-go. We're trying to figure out what's gonna happen, what's going next. I mean this is a disease that's she's gonna be with for the rest of her life. I mean the chances of them coming up with a cure, that's great if they do it, but they haven't yet, but you can't think of that so you just continue doing what you're doing, doing things as you go along. It's a normal thing, people live with it every day, and you just gotta go on.

Father #2

About a week before he got sick, I was asking about his energy level, and he just said, "I'm just tired all the time, Dad". And that made me start thinking a little bit, and he did have a little of a head cold too. But it made me a little concerned because usually when I'm dieting and losing weight, I'm feeling good, I'm feeling more energy. So it made me a little concerned, but yet he was sick also, so I thought that could be it. And then, basically, it was about a week after I started having a little bit of thoughts about it that he ended up in the hospital. He actually ended up getting an ear infection, like a boil or something, and it was Saturday morning and he was complaining about it hurting really bad, and I was at work, but I told my wife to go ahead and take him to the ER to check out what it is. And they lanced it, did whatever treatment and sent him home. And I got home that night at about 8pm, I work 7 to 7 during the day. And he came walking down the hall and I noticed that he looked really bad and then all of a sudden he started telling "Dad, I just can't seem to breathe", and he was breathing kind of odd. And that's when it dawned on me that something was wrong. So my wife took him to the ER right away, and then an hour after that they called and said they thought he was diabetic.

Ummm... well, the initial thing that happened was he ended up being in intensive care for a couple of days. He was pretty bad. I at first felt guilty for him to go that long, I felt I should have saw the signs earlier. So there was a guilty feeling on my part, ummm, and I also feel like because I didn't make him eat well enough and things like that, I felt like it probably made it happen. But as soon as he came out of intensive care, he kind of looked at me and his Mom and said "Well, I didn't want diabetes, but if I have it I have it." Or something like that. But he actually came around and he responded really well to the education he was getting from the hospital, so he's done well with that. His personality type, though, is not one to be really responsible for himself, so that has created problems with him trying to treat himself, and puts a little more of a burden on us.

Father #3

Looking back, she would complain about feeling... she was very athletic, and she would always be real jittery and almost faint. Feeling really weird, which we would always blow off as you haven't eaten anything; it's time to go eat. And then she would feel somewhat better. So we just encouraged her to stay hydrated and take a snack for after school, and then do your sports. She did, but she would still have these little symptoms. And that made us question whether she was following our rules and suggestions. When she turned 15, she didn't seem herself; she was very out there, spacy, non-focused. Rebellious. Everything that was not typical of her, and we just attributed it to the fact that she was in her teenage years and rebelling and all the other stuff that comes along with it. She was just making a lot of really bad decisions with friends and stuff. Now we understand more about what the blood sugar does to your thought process, with the highs or lows.

Overwhelmed. When I was first called it didn't hit me because I was thinking wasn't a big deal, because I was thinking about the diet side... you know you just eat different foods. So my wife stayed at the hospital with her while I stayed at home with the other three, and my wife called and said she was going to have to be on insulin. And I thought, Ok they'll get her regulated and once you're regulated you're fine. But my wife said, "No, this is a permanent thing." And then a whole lot of stuff hits you. The cost is one, but it's on the lower end. It's the availability of insulin... the economy is the pits, you never know what will happen. Up here on the Lake we get ice storms where he have no electricity, and you have to get propane or kerosene and it's not there. What happens if we have to get insulin for her and we can't get to the pharmacy to get a bottle. What if we're on vacation and I drop a bottle and it breaks. It makes you want to be a hoarder (laughs) and stockpile the insulin. Put a stash here or there, so that no matter where you are, you have some.

Father #4

Everything was normal. She just found out one weekend, she started urinating frequently, and we knew the symptoms. So we called the family doctor. He said to get her down there, they'd do the blood work and send her straight to the hospital. And she was diagnosed there.

And I'm diabetic as well. Type 1.

Well, it's like anything. You feel bad, or at least I did because I know I was probably the reason she's diabetic, because it's through the genetics. You feel terrible and wish you could take it away, but there's nothing you can do. So we settled down after about a week or so and had to learn how to deal with it.

Father #5

I remember that my wife had said simply in passing that she wanted to have her see the doctor the next Monday when we got back. She said she's got this ear infection. And I remember thinking it was nothing. So anyway, I was speaking to a large group that day, and my wife called me and said, we've got a problem here. I said, "What do you mean we've got a problem?" She said that the doctors think she may have diabetes. I was thinking that they tend to overreact. She said they wanted to send her to Columbia, right then. So I remember that she's crying, my daughter's crying, no one knows what's going on. I try to make some calls, find out who the best doctor is in Columbia, who we should call. That's how it happened.

We were in Columbia in 3 hours. Her blood sugar was through the roof. The pediatrician said it was so high, it wouldn't even register. So we got up there, the cycle began, we couldn't get an IV on her. Everyone is so excited, but I was just trying to navigate through the system. We were up there about a week. We went to Outback about a week after we got back. And my wife is giving her a shot while we're at the table, the waitress comes up and says, "Oh, I'm so sorry you're a diabetic kid." I said she wasn't a diabetic kid, she just has diabetes. I didn't want people labeling her as a diabetic kid. I was really hard on the people at school because I didn't want them labeling her as a diabetic. She's still a 17 year old girl with all the normal struggles in life, but she just happens to have diabetes.

Father #6

P: We all got sick, just with a cold. Our daughter was staying sick. We thought it was a cold, but the week before she got to where she was getting thirsty, so we took her to the urgent care in Joplin and they diagnosed her with the croup. They said if anything happens with her, get her to the emergency room. It was Monday, I went to work. My wife stayed at home with her, she called and said her lips had turned blue and she was taking her to the emergency room. So I met her over there, and she was so dehydrated, but the night before she had drunk a lot of water been back and forth to the bathroom. And she was hardly where we could recognize her when we got her there. They went into her knee to get bone marrow to figure out what was going on. They red flagged her straight over here, and she was here for three days.

I: So three days here. What was that like for you and your wife? How were you both doing?

P: It was terrifying. They told us in the emergency room that she had a 50/50 shot to live. We were scared she would die. We didn't know any of the symptoms of diabetes. There was no one else in our family, so we didn't know anything about diabetes. And it was scary. Actually, my wife's grandma was staying with us. She rode up with us, my wife's dad came up. The whole family came up here to support us. It was very emotional.

Father #7

P: It was around Christmas time. She started getting sick, we thought maybe she had the flu because she wouldn't eat so we (unintelligible). Then Christmas day she was semi-ok, semi not. The next day, I went to work and had to come back home to get a compressor for work, and I came in and checked on our daughter. My wife said she just picked her up off the bathroom floor, said she looked like she had jaundice. She was yellow-ish. So I picked her up and carried her to the emergency room. That's when they started running tests and they said they thought maybe she had to have surgery on her gall bladder, I think, and they tested her blood sugar and it was way over 800. Then that quick I was like, "Well maybe she's a diabetic." But they wouldn't tell me down there. So we admitted her to the hospital, and they told me I would have to go to Columbia the next day. So I stayed a little bit with her; her mom stayed overnight. I went home and got things packed up to make the trip up there. Come in the next morning, and that's when the doctor came over to me and said they had a problem that night. They said they had to do a test to make sure she has diabetes by not letting her have anything to eat, but her mom had given her crackers. So they couldn't get an accurate reading. So my wife went home, and I said something to her about it, and she said that she hadn't given her crackers. I said "really, they found the crumbs in the bed, and our daughter had said that 'Mom gave them to me.'" That day, she left, I took our daughter up to Columbia. I stayed with her the whole time.

I went through all the schooling and everything, and we stayed there that week by ourselves. Her mom came up on that Saturday night, and we left on that next Sunday. From then on, I'm the only one that's taken care of our daughter. Her mom always has to ask me what to do, or how much insulin she needs.

It hurt a lot. Because my daughter has a serious illness, you know.

Father #9

So it'd been 3 hours, and we didn't think anything of that simply because he had drank so much, so we changed him, cleaned him up, and then went to the funeral. And halfway through the funeral, he was leaking through his diaper again, and then 2 hours later he was leaking through his diaper again. That's when we decided we needed to call the doctor. The nurse said to only give him water, that he would pee a lot, but that they were symptoms of diabetes. If it continues, bring him in on Monday. So we took him in on Monday, and got the diagnosis that Monday.

They were trying to regulate his blood sugar. He had some ketones in his urine since his blood sugar was so high for so long. So they were trying to get the ketones out. They gave us very heavy training on what life was going to be like after we left. They taught how to check his blood sugar, regulate blood sugar, regulate his diet, calculate the insulin dosage, all those things. We went to classes learning about all this stuff.

So after the hospital stay, we left on a Friday. My wife went to work on that Saturday because she had been out of work and works on a commission. I'm on salary and had vacation. So I stayed home and handled the first day by myself. And then when she got home, I kind of helped her. Being the mother, she was really worried and really analytical when it came to "Am I doing this right? Am I missing a step?". So I just tried to be there for her and calm her as much as I could, and walk her through those things. Then that Monday came, I went to work, she was off, I obviously made myself available by phone if she needed anything. But we just kind of got into a routine.

I mean, it is what it is. I had to step up and work with my son, or sit back and not have any to do with it. That's not the man I am. I stepped up and took the role of the father, I was strong for him, strong for me. You've just gotta do it.

Father #10

We have struggled. It's been tough. She is very involved with the diet, the carbs, and all the portions and restrictions. It's been tough for us, it really has. The first week he was home, she didn't want him to leave the house. It's been tough.

Father #11

Well, we had an only child. She'd had various different health problems pretty much since the time she was born. We dealt with that a lot. We were a pretty close family. We really didn't pawn off our daughter on grandparents or anything of that nature, or babysitters. We really included her in our lives and changed our lives around her. She was pretty portable, is what I always said. Pretty portable.

Like I said, the two of us have always been pretty close, and she's always been close with her mother, but I have always been involved with her, in her care and raising and taking care of. For example, when we first had her, I worked Monday through Friday and Jennifer had a job where she worked weekends. So it was our daughter and I all through the weekends through the first two years. So we were always very involved.

We kind of half noticed she was eating a lot and then 30 minutes later she was hungry again. The other thing was that she was going through a lot of toilet paper. We were living in the Springfield area and we had come home before Christmas, which was an hour and 20 minute drive, and had come to notice that we couldn't drive very far without her having to go to the restroom. So we half talked about whether something was maybe wrong. Like I said, she had had some medical issues prior to that, she'd had a lot of ear infections and had ear tubes put in. We thought next time she goes to the doctor with an ear infection, we'd have her tested out there. Sure enough, early January, I was working and my wife was off, so we'd had lunch together. My wife called and said our daughter's

ear was hurting, and so she took her to the pediatrician. About 3pm, I got a call saying I needed to come home, that she'd tested positive for diabetes, or her blood sugar was high.

Our daughter was coping really well. My wife was pretty upset, and I was as much in shock as anything.

Father #12

Well, he started to sweat and urinate quite a bit, and was kind of feeling not so good, for like a week. And we were thinking there was something wrong with him. And so we decided that we would just check his sugar to see what was going on. So we checked his sugar using a relative's meter, and you know how they go up to 600 and then say "high". Well it read as "high". So we went to the doctor and they said he had type 1 diabetes and they sent us home with some pens.

She took him. I don't go to a lot of the doctor's appointments because where I work, if I'm not there I don't get paid. She works salary for the court system. So she can take off time.

They sent him home with the insulin. And there is a story behind that. We got him home, didn't know what in the world we were doing, hadn't had any training on it. And we started with the insulin pens, had trouble with them, and he got really bad sick. Then we went to the hospital and they put him in the children's ward and he was there 7 or 8 days, I think. They got him straightened out. I went to that, but I wasn't there the whole time. I think we went through about an 8 hour class where they showed us how to give insulin, use glucose tablets and shots if he drops too low. They gave us the full tour, and that's where we got a lot of the learning in.

Father #13

Actually, my wife noticed that he was losing a lot of weight, which I just assumed was him losing his baby fat. But he was eating a lot, always hungry, always thirsty. We caught it a bit early, because the doctor said they are usually really sick when they come to the hospital the first time, and he wasn't sick.

It really wasn't too hard. It was mainly difficult with it being a child, it was kind of upsetting. We had to adjust to the emotional side more than anything.

Basically, it just took time. We both thought that we were the cause, we did something wrong. The doctor told us that it's nothing the parents do. That it just happens at random, and we just had to deal with that. It just takes time.

Father #14

She had not been feeling well. It was during Christmas break. Her mom thought she might have a urinary tract infection. We went to the doctor and they ruled that out, did some blood work that morning, and we left. They called us that afternoon and told us we needed to check her into the hospital. That was the 26th of December, the day after Christmas, and her birthday was the 27th. She had to spend her birthday and the rest of her Christmas holiday in the hospital. It was kind of a shocker to us; we went in thinking one thing and ended up checking her into the hospital that evening. We spent the next 10 days at the hospital.

There was a lot of fear. Her grandmother had diabetes, and was completely non-compliant, so what she had gone through was kind of scary for us to see. So there was a lot of fear, but the doctor's group was reassuring, and walked us through everything, so that was comfort. It was a comfort that we were all there together and could go through it together.

Father #15

You said that leading up to the diagnosis, he had been experiencing some flu-like symptoms, and so you took him to the doctor, but the treatment didn't work. So you brought him to the doctor again, and it still didn't work, so he ended up in the hospital ICU. So during that time, how were you and your wife responding to his health problems?

Like I said, early on we didn't think much of it because we thought it was the flu. When it didn't go away, we did what the doctor told us to do. What made us take him to the emergency room was that not only was he doing worse and losing weight, but then he started having problems breathing. At that point we went to the emergency room. We took turns dealing with the situation as it started. Sometimes, if she had to deal with the baby, and I was home, I'd take over with him, and we'd switch off with that.

In the emergency room, once he got into the check-up room, the nurse was sure what it was. They checked his blood sugar and it was 717. Yeah, he was really laboring with his breathing. When the nurse said it was diabetes and we should have gotten him there sooner, my wife kind of lost it because we had been sitting in that waiting room for an hour and a half before he got in.

I tried to keep her calm and reassured her that we did what we could, and we did what the doctor told us to do. We did as well as we could do.

I was very concerned for my son. I was upset with us too, inside, but really upset with the doctor. That's what the doctors are for, to try different things instead of just saying it's flu and sending him home with medicines.

Well they said they didn't have what they needed to deal with his case there, so they were going to send him to the big hospital. They were going to airlift him, but in February it wasn't a good day to fly, so we went by ambulance up there and they put him into ICU.

Balancing Work and Family Demands

Father #1

She went home once or twice, I stayed there pretty much, I'd go home one night, and she stayed one night. You had to get a break, get stuff, do things, because we had other kids, a lot of family support and stuff, so we've got people around. Right off the get-go, we did all the stuff in the hospital, shots and stuff. Starting out, she didn't really want to do anything, but as soon as we got home, she wanted to do it. For some reason, she didn't want to do it in the hospital, so whatever.

So when we got home, she started doing her shots, we'd periodically do it, but I couldn't tell you that last time we give her a shot; she does it all now by herself. Pretty much, she's been doin that for 5 years.

Father #2

Pretty much both of us. Ummm, I will, depending on my work schedule (if I'm at home) I pretty much do morning and night. On the days I work, I usually give him his morning while he is still in bed, because he gets up about 10 minutes after I leave, if it's a school day. I pretty much get up, and right before I leave, I check his blood give him his shot, and then he wakes up about 5-10 minutes after that. And then that evening, because I get home so late, Mom takes care of it.

If they're going to school and I go to work, and I check his blood and give him a shot, and I'll usually write that down because he can see where it was. And then, I'm gone the rest of the day because I work 12 hour shift, so he will walk out and meet the bus for school. Mom makes breakfast and then makes his lunch; he doesn't like to eat school lunches. At school, he just does a blood check at lunch, and then when he gets home usually before dinner he'll do a blood check and then mom and he will try to figure out how much insulin. If this blood checks high, they'll usually call me and I'll try to tell them what insulin he should take.

Father #3

So my wife stayed at the hospital with her while I stayed at home with the other three.

Put a stash here or there, so that no matter where you are, you have some. We've already had situations where I thought she grabbed it, she thought I grabbed it. And we're up here and getting ready for a baseball game and whatever, and now we have to go home, get her insulin, get her back, feed her. We have all these timing issues where they have to eat within 30 minutes of taking insulin. Eating needs to be at about the same time each day. And now she's started track and they had their first meet, and she needs to bring food to eat, and take her shot. The meets are over at 7:30 or 8:00pm, so we're already an hour past. The doctor stressed the day I met you that she has to eat more consistently. All the kids are sportsy, it throws off our eating schedule. Barb has to just eat when it's time, the others have to just eat when they can.

Father #4

We had to adjust to sending needles with her, making sure she got her shots on time.

We don't live a scheduled life, so a lot of times, and this is the reason I'm on the pump, I was having a lot of trouble with lows. We own funeral homes, and there are a lot of times you're in the middle of a funeral, but you can't stop and eat. Your blood sugar gets low

Father #6

Now, she stays home during the day while I'm at work, so she takes care of her through the day, and I get up and check her at night, give her her shots and such.

I mean when she's sick, or when I'm sick, we'll change it. She'll get up in the middle of the night. Lately we've been doing a lot of work on our house, so it's been really hectic, but I still get up and check her.

My wife does the majority of the housework. I get home around 5-ish. We eat dinner, then play with the kids, watch a movie sometimes. Sometimes she needs a break after being with 2 kids all day long. She may go spend some time with her friends.

Well, when I get home earlier on Fridays I get to help out a little more. So that helps out, I can give her a bit of a break. She's at home with both girls, she can't watch our daughter outside. I don't like her being outside by herself. What hinders my involvement is working overtime, or if I have to go out of town. If I have to go out of town, I don't know what's going on except for phone calls.

Father #8

I had to work and couldn't be there, and we didn't have anyone else who could help, so it was pretty much all on my wife to provide the care.

Father #9

We switched off nights. We had a newborn, so we had to take care of her. I'd go home with her, we'd come back together the next day and my wife would go home with our daughter that night while I stayed in the hospital with our son.

So after the hospital stay, we left on a Friday. My wife went to work on that Saturday because she had been out of work and works on a commission. I'm on salary and had vacation. So I stayed home and handled the first day by myself. And then when she got home, I kind of helped her. Being the mother, she was really worried and really analytical when it came to "Am I doing this right? Am I missing a step?". So I just tried to be there for her and calm her as much as I could, and walk her through those things.

Then that Monday came, I went to work, she was off, I obviously made myself available by phone if she needed anything. But we just kind of got into a routine.

Yeah, it's changed just because we're on a different shot regimen and she's not working. So typically now it looks like, since she stays at home with the kids, she'll give them breakfast, give our son his breakfast shot, give them lunch, give him his lunch shot. And then when I get home, I'll usually help make dinner, and then give him his dinner shot. And then I'm typically the last one up in our household. I'm a full-time student as well as working. So usually I'm in online classes, and when I'm done and getting ready to go to bed, I'll give him his night shot.

Father #11

Well at various times, one or the other of us has taken the lead. I always pretty much took care of her in the mornings. We'd both get up and go to work. So for example, I would get up first. I tested her sugar, gave her her shot. And this happened every morning until she started giving herself shots. At noon, depending on where we were at, my wife took some time off to take care of her. In the evening, she would make a meal and then I would check the blood sugar and give the shots.

Father #12

He was there 7 or 8 days, I think. They got him straightened out. I went to that, but I wasn't there the whole time. I think we went through about an 8 hour class where they showed us how to give insulin, use glucose tablets and shots if he drops too low. They gave us the full tour, and that's where we got a lot of the learning in.

We did injections for a while. I wasn't around for the morning or noon checks and injections because I was at work, and then summertime Tiffany would give the shots, do all the shot stuff.

Father #13

Well she works nights and I work days. Whenever she was home she would do a lot of it, whenever I was home and she was working, I would do a lot of it through the night and in the morning.

Otherwise he usually takes care of all his insulin administration, and his tests on his own.

We basically do a lot of the carb counting because we're usually making dinner anyway, so we do the counting.

Decision-making Regarding Work Demands*Father #2*

The good thing about the department I work for is if there is some sort of family matter or something you need, they go out of their way to make sure you get what you need or whatever. Since I work 12 hour shifts, I have a lot of days off so scheduling our appointments on my days off is not very difficult. And if there's something I do have to go to on a day I'm supposed to work, if I have enough notice, it's easy to get that time off. So that works well. Having the insurance coverage of course helps, but as I say "good insurance is not what good insurance used to be". So we have to pay a lot of money out of pocket still. And the kind of work I do, I can't just answer the phone every time he calls. I try to if I see that it's him calling... my whole family is pretty good about not calling unless they really need something. So if I see that, I try to call back as soon as I can.

Father #4

You don't get to spend the time you want to with your kids. We get tied up getting involved in getting everything done. We don't download her pump as often as we should so we can help her stay on top of her sugar. When you own your own business, it's a busy thing. It takes overtime, which keeps you from spending time with your family. There again, the people we deal with to me are kind of like family too. Our kids understand that. That's one thing... they've always been involved in our business.

We own funeral homes in 3 small towns, and so I hate to be this way, but we're at everyone's mercy. We've been married 25 years, and had one vacation. We don't take vacations. If someone dies, you take care of the family, take care of what needs to be done. We make sure the kids get to do the normal things, that they don't get put out by it. A normal day for us... we like to be home when Hannah comes home from school, but some days we don't get home until 5pm, 5:30. But we usually try to be there when she gets out of school. We own the business, so we try to make arrangements, but there's

times you can't be. It's kind of a hectic life. There's a lot of dropped plans and things like that, but it's just something you deal with.

Father #5

I've always been a workaholic, work probably 60-70 hours per week.

To be totally honest, I think there are times I think I have to work even harder because I have a daughter with diabetes, and you don't know what the outcomes will be. You don't know what the future is going to hold. Sometimes I feel like it drives you more to do well, be successful. A lot of guys take financial risks, career risks, change jobs, go to work for other companies. Sometimes I feel like I'm a little more on the safe side about things like that because of my daughter's illness.

I think with the way my job is, I'd still be less involved. If my job changed and I was home more, I'd probably be more involved. I think Bev wants me to be more involved, do a lot more things, but I've said to her you can't travel 6 days a week all over the states and be more involved.

I work for a guy who has never once asked about my daughter. If I called him up and told him I need to go to another town for a week, it would not be a good conversation. I could make it work, but it would be difficult. It's a decision I've made though.

Father #6

Well, when I get home earlier on Fridays I get to help out a little more. So that helps out, I can give her a bit of a break. What hinders my involvement is working overtime, or if I have to go out of town. If I have to go out of town, I don't know what's going on except for phone calls.

They tend to work with me if I need to get off to help out, or go to an appointment. They let me make up hours. I'm really blessed.

Father #8

Well, I have a flexible schedule, so I'm able to provide *some* help when I'm at home working, but not that much. I can't do it as much while I'm actually working on the phone or computer.

I mean, when I need a day off, I can take one whenever I want, so it works out just fine for me to take our son to a doctor's appointment if I need to.

Father #9

My work is flexible now. When he was first diagnosed, it wasn't. I was sales manager at a retail location. When I was there, I was there. I was usually there anywhere from 5:30am to 7pm. Now I have a more flexible schedule. I'm on the road, but I have time to check in with the kids and call the wife and talk to her. Sometimes I work out of the house, so I'll be on the laptop at home, but at the same time if the kids want to come in and talk, I'm there for them.

The job I took is a lateral move. It wasn't a promotion, just a different channel of the business. But I knew it would give me a little more flexibility for family time.

Father #11

I'm the vice president of a bank. Having an office job, there are times I have meetings that I have to go to, but I also have some flexibility. So I can take extra time during the day to check on her, or fill some demand. I have more flexibility than a lot of people do. Unless I have to give a presentation or something, even if I'm in a meeting... for one thing we got our daughter a cellphone when she was young. So she can send me a text and I text her back. I can step out of a meeting for a few minutes to talk to her. So far every place I've worked they have been understanding and it hasn't created any issues.

One time when we were in another town, the school nurse had to call because our daughter wasn't feeling well. So I just packed up and went to get her, spent the rest of the day with her. When I can't do that, I may take her over to her grandmother's house while I finish up a few things at work. I can also use it to go to the doctor's appointments every few months.

Where my wife has to have thirty days notice because she has to schedule patients, spur of the moment things are difficult for her to attend to, but I have that flexibility.

Building Trust within the Parental Treatment Team*Father #1*

Ummm... I would say probably 1 more than likely, maybe a 2 certain days. I'm sure we have days that are a 4. But I'll tell you the majority... we've been together 24 years, we've got 4 kids, she's not afraid to speak her mind, but we know that in the end we agree and we do what's right. So I'd say a 1.

When I'm not here we talk on the phone every evening when 24 hours at the fire department, so we always touch base, I always know what usually happens at home, so even when I'm at work, I know what's going on.

Father #2

It was kind of shared between, pretty much right away it was shared between both of us. I kind of caught on to the training quicker than my wife did, she didn't really catch the concept of how to adjust the insulin and such, so we had to kind of continue that.

It'd be fair. I mean part of it is that in the beginning she went to all of the same classes as me, we went to the same training, but she just wouldn't get it. And it hit the point sometimes where it's like "I can't do it all. You're going to have to understand this." And, you know, she has a different perspective on things, she doesn't understand the stresses I'm under, and I probably don't know what she's under. And then sometimes it's the differences in her way of discipline over mine. My way of discipline is you do something wrong, you're in trouble right now, and it's over. Her way is she'll bring it up for several months, just, me and the boys, just talk you to death. And just like most of us males, we don't respond to well to that, and neither do our kids.

I think in our relationship, it's not just with the diabetes, but the way we take care of everything, a lot more of it is left to me. And especially since she doesn't really understand how that insulin responds in his body, so he'll still have to call me. I think it's just her inability to... ummm... treat or tell him what he needs when there is a problem creates more pressure for me. Cause sometimes if I'm at work and they call me, I can't answer right then or I can't call right back. So it's something I need them to take care of, and I need them to take care of it properly.

Father #3

When she is home she takes over. She just jumps right in, and I don't worry too much about anything. I make sure we eat really well, especially on the weekends. My wife likes to do Sunday cookfests, making enough so that we have leftovers to eat through the week. I'll bring some of that to the office. We live 10 miles out of town, so we'll eat food here and then go for their activities which are also in town. So my office serves as a small base for food and activities.

Because we're always on the same page. Even though she travels a lot, we're always talking everyday. There are sometimes we disagree because I'm here with them and I see the attitude, and I say they have to do this before they get to go out and have fun, but she's like "Let them go out and have some fun." That's our biggest thing is getting their chores done. She'll want us to all go do something even though we have so much to do at home. She gets so little time with the kids that I usually just try to bite my tongue and go along with it.

I guess it's like an extended arm. She can't do it herself, so I go do all the stuff with our daughter and the teachers, and then consult with her. She's more the educated one that when I come back with everything I've learned from them, she'll think of questions I didn't think of asking, and I'll make a note of it to call them to ask. She helped me a lot when our daughter was sick, helped with the formulas to figure out how much Humulin R she needed. So she's in the middle, and I help keep her informed of daily activities of what's going on with the kids. So I video the track meets so she can still feel like she's part of it. Just like any parent who can't be there when their kids are doing stuff, she's just sad she can't be there.

Father #4

Well, because we do everything together. We work together, she's my best friend. We love each other. We have a strong family structure. We go to church. For me it's almost perfect. And she puts up with me (laughs).

Father #5

I've always been the type who was more of a friend. My wife does most of the parenting, before and after. I think she's kind of the rock of the family.

I don't think both parents can be 150% involved. I think one parent has to take a step back. I think most mothers tend to have an emotional bond. They hear what they hear and see what they see. I try to take an outside few, and say "Here's what we need to do. Here's where we're at. Let's put out the plan, let's do A through C."

She's my best friend. I think good. I think we have a good balance. When you marry someone you love them. But when the bad times happen, we remember that. There are bad things that will happen, but I think we have a good relationship where we can step out the marriage and ask, "Well as my friend what would you say to me?"

I'm not really involved in the day-to-day management of her care. In fact, whenever my wife takes a vacation, she has back-up plans to take care of her. I'm probably more... I think she lets it identify who she is. I think she lets it absorb her. I think we're not a diabetic family, we just have a beautiful daughter who has diabetes. I tend to let it go as just a chink in the armor.

It's my fault. Unless it's a red flag, I tend to... cause sometimes I only have 5 minutes to call her because we'll meet until 9 or 10pm. I'll call her and she'll say what happened at the appointment with Dr. Bachrach or something. I need to be more involved.

There are times she'll be gone to a conference or to a friends. She'll say I need you to be home. Sometimes she'll tell me that 3 months in advance, and my calendar looks really great, but then I get pulled into a situation where I have to be gone and I know that's disturbing to her because now our daughter will be home by herself. So she has her mom

come up, or her sister, and everyone just kind of accepts the thing. In a way it makes me think, “(Unintelligible)... am I a crappy father. You have to get your mother to come up because I’m not reliable.”

I: How do these back-up plans help or hinder your involvement?

P: It helps her treatment, but it provides me with excuses not to be involved. Sometimes I wish Bev would say to me, “You’re going to be here, and if the job lets you go because you’re here then fine.”

Father #6

Well, when I get home earlier on Fridays I get to help out a little more. So that helps out, I can give her a bit of a break. She’s at home with both girls, she can’t watch Paige outside. I don’t like Paige being outside by herself

I call everyday at noon to find out what her numbers were, just make sure she’s doing ok.

No, she’s pretty good at what she does. I would say that she is on top of everything. She’s a little better at it than I am, figuring out the numbers on food. She’s got it all memorized pretty much, with her preparing food all the time.

I think it’s excellent. We sit and talk every night and discuss our problems. Of course we get into our arguments, mainly around how we deal with the kids. Not all the time, but we have a very healthy relationships.

We sit there and we back each other up on it. If I have a problem figuring up stuff, she’s right there with me helping me out. If I’m watching the girls by myself one day, I can call her any time and ask her how to figure something up and she helps me. Everything, she’s always there for me.

We call each other everyday at noon anyway to find out how the numbers looked that morning and if I need to change anything at night when I give her insulin.

Father #7

I’d come home from work and she’d leave. That’s what it was like through 13 years of marriage. I would take the girls bike riding or fishing, I’d do all that with them. I’d take the her to all her diabetes appointments. Until last August, that’s the first time that she ever had her mother here.

So Tabitha went home, and I said something to her about it, and she said that she hadn’t given her crackers. I said really, they found the crumbs in the bed, and our daughter had said that “Mom gave them to me.” That day, she left, I took her up to Columbia. I stayed with her the whole time.

Yes. I went through all the schooling and everything, and we stayed there that week by ourselves. Her mom came up on that Saturday night, and we left on that next Sunday. From then on, I'm the only one that's taken care of her. Her mom always has to ask me what to do, or how much insulin she needs.

My ex has stepped up lately because I would not let her... she didn't have any overnights until last year. Because I didn't feel she had the ability to take care of our daughter.

I've asked to know what our daughter's numbers are. We're supposed to be taking a notebook back and forth so I can see where she's at, but I haven't seen the notebook in two straight months. I asked our daughter, "Oh I forgot it." I ask my ex, she says "You keep the notebook at your house and I'll keep mine". That's not what the guardian ad litem asked, she told us to transport the notebook back and forth. I've seen what's in that notebook, there's not enough information there. There's a lot of highs with no corrections.

Father #8

I had to work and couldn't be there, and we didn't have anyone else who could help, so it was pretty much all on Sam to provide the care.

We communicate as much as is necessary. If there's no issue, there's nothing we discuss. If his blood sugar spikes or drops low, she'll call and we'll figure out what to do together.

I think we have a fantastic relationship. I think we work well together. Handling the diabetes has been difficult because it adds a lot of stress to our lives. There's a constant anxiety that hangs over everything, but it draws us closer together. Well, I don't really know. I love her and love him, and will do whatever is necessary for either one of them. If it's helpful to my wife for me to take care of him instead of our daughter, I'll do that. I'll do whatever is necessary.

Father #9

I'm a really driven person. I want to do my best and work hard at anything I do. That obviously includes being a father. He's my offspring too; it's not the mother's responsibility, it's both. I have a pretty traditional outlook on marriage.

I'll usually check on his blood glucose. But that's become a way of life. She trusts me when I'm home alone with him, and I trust her. I don't try to undermine her and ask her a bunch of questions to make her feel like I don't trust her to do her job.

I mean, we're always working on our relationship communication-wise, and everything else. Sometimes it's hard for a mom with two kids to put as much as she'd like into a

marriage. When there are kids around, that kind of hinders the communication. It takes away from the wife and husband time.

Like I say, it's just one of those things we have to do. There's no question of whether or not we can do it; there's just a demand that it has to be done. We don't let anything hinder his treatment.

There are times when she stays at home all day, and she needs to get away and go see her mom or her friends, and I allow her to do that... well I don't want to say I allow her, I'm sorry. She does that, and I agree with that completely. Everyone needs their adult time.

Father #10

Never any issues, never any problems. Our big thing is flexibility, and we are very flexible for each other's families. Our son has siblings on the other side, too. he is the oldest of 5 siblings. He's always been involved in everybody's upbringing and stuff, so birthday parties, we all spend together; family events we all spend together, you know Christmas Thanksgiving, Easter, Mother's day, it's always been an open door policy between both families. Everything works out well.

You don't see that type of interaction a lot. It's all about our son; it's all about how he's taking care of it. It's beyond anything I see from folks that are in these types of situations with blended families. I mean, typically someone has something poorly to say about one another, but we're just not that way. We don't really... if I had one word for it, for me it's "outstanding". We just don't dwell on anything. It's all about him.

Each family eats a little differently. My ex and her husband own a bike shop, I run a recycling yard. So we're all really busy. Each family had a different take on it of how they were going to do it, but the end result was still the same. When he's at Nicole's, this is how they do it, when he's at my place, this is how we do it. It's basically the same thing we learned in the classroom; we just took it home and applied it. We listened to everyone about how this would affect him, and how to keep the negative things at bay. Are we going to have two sets of insulin? Are we going to have dirty needle drops at both houses? We decided we should have a traveling system. As for portioning scales and stuff like that, each family has its own means. Sharps containers and such, each family has its own, including the grandparents. We involved our entire families.

Father #11

Well at various times, one or the other of us has taken the lead.

We got married older, so we've had... we really don't argue or fight. We get along, we have similar beliefs. We don't have drama at our house.

We've never disagreed on anything I can think of. There have been times when one of us has picked up the burden, and then other times the other one has, but we've been very fortunate with the two of us. One of us has never been overburdened being the primary caregiver.

There were times when Jennifer was going to school, and was writing a paper or studying for a test, and she needs to concentrate. I pick it up then. Or maybe we've bought a couple of banks at work, and she picks up the slack.

I think whenever I was raised, there was a very distinct the husband goes to work and the wife takes care of the kids. That's probably the way she was raised too. But for us, that's not the case. We're a family unit and we all do a little of everything. I may mow the lawn, which she rarely does, but I enjoy mowing the lawn. I remember when our daughter had one of those ear infections, and her pediatrician had a morning session. I remember me taking her during the week, walking in, looking around and seeing 3 other men with their children. I remember thinking this is kind of neat and quite different from when I was growing up. 30 years ago, it would have been all mothers. I think we're more involved in the domestic aspect of the home life than previous generations.

Father #12

If we have trouble with a pump, or need to change an injection site, my wife handles it. I have a fear of tearing it up or doing it wrong. The last two times I changed one, the first one I put on each time was bad. It wouldn't take the insulin.

I can do it, but I like to have her do it, that way she doesn't gripe at me in case I tear it up (chuckles).

Well, (chuckles) my wife's a go getter, and she just did it. Well not necessarily that she took over. We've always been involved together. It's just that she had the time for it, where I didn't have as much time.

She tells me what's gonna happen and I say ok. She'll go to the doctor's visits and tell me what me need to do and how it is, and I say "OK". She's the boss.

And I should say I'm not as fluent on it as I ought to be, but since he's gotten older, he can handle it by himself. I'm not that computer literate. I can do it, but it takes me a little time. I don't keep in practice.

I don't know it all, and I've forgotten a lot of it, but I know enough to get me in trouble.

Father #13

I would say it's a 5. We've always gotten along. I don't think the diabetes has done anything different to the way we interact. We have to work around the counting carbs and stuff. We have a set schedule of how we work around his treatment, but our actual relationship hasn't really changed.

We just try to raise the kids in the best way we can in the proper way. We're both kind of mutually involved in everything; we just kind of do everything together.

Father #14

I think it's more than one person can do by themselves. It's something that affects the whole family, so the whole family has got to be engaged and know what's going on. I think I learned early on, having a daughter, all the things you don't know about women are pointed out to you.

We just, like everything else, if Taylor needs something that I didn't get a chance to do it, she just does it. And vice versa.

Father #15

I think a 5. I'm sure it's not that way 100% of the time, but we don't fight in front of the kids hardly ever. Arguments are private conversations. I don't think the kids could tell you the last time we fought.

It's a teamwork thing. How are we going to make this work to make it as normal a routine as we could. We just looked at what we had to do, and said "Who wants this?", or "Can you do this?". From the beginning, it was collaborative. Our son's pretty laid back and flexible about most things, so we just get it done.

Like I said, it's a team effort. She's always wanted me involved, and I've always been willing to be involved. With wanting me at the appointments, I think she doesn't give herself enough credit, but because I have a college education and she doesn't, I think she feels that I can understand what the doctor is telling us better and ask the right questions. It's been a shared deal from the beginning. Never once has she said "this is my responsibility", or "don't do it". It's been a pretty easy deal in terms of who's going to do it or not; it's just who's available. Like I said, with my schedule I'm more available than most dads would be. I think if I wasn't as available, what would happen unfortunately because there would be no other way, the mother would do it. But in our case it's a shared deal.

I don't want to push her out simply because I have a need for control, which I really don't.

I'm head of the household, and it's my responsibility to take care of the family. Primarily that's financial, food, shelter, medical care, and all that. But I'm also the disciplinarian. My wife takes care of them when their sick and mothers them if you will, I hate to use that phrase. She's the one that picks out their clothes and all that. We each have our own duties, but I'm not an absent father, and she's not an absent mother, so the kids get a lot of attention.

The other thing I would say is that my father worked two or three jobs to take care of the family, so he wasn't around much. I promised myself I would be more involved if I had the time. Thankfully, I have had the time, so I'm involved everyday unless I'm gone on a trip. Neither one of us see it as our job and our job alone to do anything with regard to his treatment.

Encouraging Child Responsibility

Father #1

Starting out, she didn't really want to do anything, but as soon as we got home, she wanted to do it. For some reason, she didn't want to do it in the hospital, so whatever.

So when we got home, she started doing her shots, we'd periodically do it, but I couldn't tell you that last time we give her a shot; she does it all now by herself. Pretty much, she's been doin that for 5 years.

There's a point there where you have to let her do it, and she does pretty much, but as a parent you still have to try to look and she gets irritated every time we ask her, "Did you do your shot? What was your blood today?". You know kids are kids, it doesn't matter if they have diabetes or not, they feel frustrated when parents ask them questions, so that's part of it, but other than that, now it's just a routine thing. You just continue on and make sure she gets what she needs.

I mean that's our job I think is to bug her and give her a hard time. And I jokingly say that, but it's true, I mean you ask her questions. If she's at school all day, two of the questions she hates to hear is "Do you have any homework?" and "What was your blood?" So I mean, she gets frustrated, but as far as that goes you have to make sure she's entering her blood stuff, you know we ask questions just like any other normal parent probably should be doing.

Father #2

His personality type, though, is not one to be really responsible for himself, so that has created problems with him trying to treat himself, and puts a little more of a burden on us.

He checks his own blood sugar and tells us what it is. Of course that can be a problem sometimes. Sometimes he doesn't want to check it and he'll just fib. Which, he doesn't like the finger pokes, it just bothers him.

He's good at another thing, when he does go low, I'll hear him get up and he'll come and tell me that he is low, and he gets a snack. And then he lets us know in case something happens.

Sometimes I have to go check the meter to see if he's telling the truth.

He can do the shots himself, he just doesn't prefer to. He's had issues like that of just general responsibility, us having to tell him what chores to do, taking care of himself. I'm a fairly strict parent, and as he has gotten older, I try not to be as strict, but I still make him do what he has to do. One of the things I do find though is I'm very much if you don't lie to me, whatever you did or didn't do may or may not get you in trouble, but if you lie to me, you're in trouble.

I didn't want to put too much on him mentally since he was handling it so well, but that may have hurt with not making him as responsible as he should be. He will tend to sometimes just straight out lie about it; he'll make up a number and then if I go check out his meter and if it's not in its memory then he admits to it. But I usually just do some explaining to him about the repercussions of that, but not me gonna spank you or get mad at you, it's "that's gonna hurt you in the future". He kind of has that understanding and has gotten better at it, but it's difficult. He knows the importance of doing it, but he doesn't quite have the eagerness or whatever to fix that. We have to monitor pretty close.

Father #3

I wanted to make sure she got it, so I would stand there and watch. Now she takes the bottle wherever she goes, and she'll call me and say "I'm going to have _____ take me to the show tonight." And I'll say, "Where's your insulin, where's your meter?" That's probably the only thing she's been a little bit lax in, the meter, she's misplaced it a few times. But I keep one here, we keep one, in the van, and one at school so she's got access to a meter if she doesn't have her personal one.

Father #4

The things that she's going to have to do, the doctors put her on shots. We had to adjust to sending needles with her, making sure she got her shots on time. Then, of course I got

the insulin pump because I'm diabetic also. And after she was doing well with the shots, we thought it'd be more convenient and better, but sometimes we wonder now if it wasn't, because it seems like anytime she gets an advance she takes it that she doesn't have to do as much, so she tends to slack off a little when her blood sugars creep up.

Well, you tend to think the pumps better, so you kind of slack off on checking because when she did shots we made sure the insulin was in her system, she was on more of a schedule. Now she does it more for herself, we tend to back off. Of course, her being a kid, that's a lot of responsibility for a kid, so we let it slide. It's like anything. I can understand, I'd hate to be a kid and not be able to eat anything I want when all my friends are eating anything they want.

She got to where after a while she was doing them herself, but when she was 8 years old, she didn't want to do it. By the time she was 9, she was doing most of it herself. We would draw it up for her to make sure she got the correct amounts and everything, but she would actually do the injections. But there again, she was giving them all in her stomach, but we needed to rotate. So I would give them in the back or arm.

It was probably our problem because we allowed her to take more responsibility for herself. Being a kid she let a lot of things slide. She doesn't check her blood sugar as often as she needs to. We put a lot of responsibility on her because we could do it for her without her learning, but she's going to have to do it sooner or later on her own.

She looks at it to see what it is, because every 5 minutes it does a reading. It's not as good as pricking your finger; it's not as accurate. But if it's extremely high or something, she goes ahead and pricks her finger because she needs to know the thing's accurate before she does the insulin.

Father #6

P: She did not like the shots and finger pokes. But now, she gives herself shots and handles it like a trooper.

I: So she gives herself shots. When did that start?

P: That started last year. She thought she wanted to try it, and we worked with her. We don't let her draw the insulin, but we let her do the injection, make sure she does that right. We don't let her spend the night at anyone's house because a lot of them don't know anything about it, but we let her friends and cousins and such spend the night. She's been really good with it, though.

Like I said she's really good about it. She's actually an easy child because she knows she has to have the insulin. Every once in a while she may give a little trouble when she's

playing with her friends, but for the most part she does what she's supposed to. People try to offer her candy all the time, and she knows she can't have it, and doesn't take it.

Father #7

I'd tell her that our daughter needed x amount of units of insulin, but then it got to the point where she was eating whatever she wanted, and she started spinning out of control. She has spun out of control a lot.

She has started doing them herself, and I've been trying... well the guardian ad litem said they want her to start getting more independent in doing that, so that's what I've been trying to do. But when I try to get her to do it, I get defiance. If I ask her to check her blood sugar, she says she's going to do it, but she doesn't. She measures her food out, and we usually eat at the house. I'll do as much cooking as I can. This weekend we found out she was saying she was measuring, but she wasn't measuring herself correctly. We're having to monitor that very closely because she's not watching what she's supposed to be doing. Last Wednesday night before we went to church we gave her monitor, and she's takes blood sugar tablets with her. When we came back, and found that her numbers were high. My girlfriend gave her a brand new bottle of glucose tablets, and there were seven or eight out of it. We asked her if she had eaten any of those, and she said she hadn't. So... pause... this is all turning into a custody battle.

Father #8

P: None really. We just did it. My wife did most of the injections, I helped, and our son eventually started checking his own glucose.

I: How long has he been doing that?

P: 1 year. We have tried to keep him as involved as possible so that he develops some responsibility for it.

We were having trouble giving him a fine enough dose of the insulin. His insulin sensitivity was pretty high, so he needed just fractions of a unit. It was hard to give him an accurate dose.

We didn't want someone else giving him shots, like the nurse in Kindergarten. Plus it gives us much more freedom in food and eating, controlling his blood sugar is better.

She is still with him primarily with it being summer, and I am more involved in evenings and weekends. But she's still the primary one. But really whoever is there is the one who gives him the bolus with the pump, checks blood. It could be either one of us.

There's not much else he can do right now. Like I said, we encourage him to do his own glucose, but we don't let him change his own injection sites, or chart his blood glucose or boluses. We just want him involved in whatever he can do. As he gets older we will

continue to add to what he can do. Ideally, I'd like that done as quickly as possible. There will be a time when he does it all on his own, and our job is to train him to be ready for that.

He does a good job, he's very cooperative. The injection sites are a bit of a challenge because changing them is painful to him. So trying to move them around to different sites is still something we're working on, and will probably be working on that forever. So I think that's the only thing that really is an issue for him.

Father #9

Well, for finger pricks we say "We've gotta check you", and he puts his finger out, no fear, no reservations about that anymore. With shots, it's kind of become a game, if he sees us getting the syringe ready, he'll go out and try to hide and say "no shots" and he'll try to run. But when it comes down to it, we'll distract him and talk to him while we're giving him the shots. It's not kicking and screaming and crying anymore.

Father #10

He is in charge of his own treatment. We just monitor it. It's his diet, and we need to stay abreast of what he is doing, but at the end of the day it's his disease. We entrust our kids to make good decisions, and we try to coach them along as best we can. We never said,

"OK, you're in charge of this and I'm in charge of that." It was, "OK son, you're in charge of this. How can we help you? Do you need Mom to wake you up at 6am so you can check your blood sugar? Do you need Dad to give you the shots? Do you want to do the shots?" You know, we're a support mechanism for him.

You don't see that type of interaction a lot. It's all about our son, it's all about how he's taking care of it. It's beyond anything I see from folks that are in these types of situations with blended families. I mean, typically someone has something poorly to say about one another, but we're just not that way. We don't really... if I had one word for it, for me it's "outstanding". We just don't dwell on anything. It's all him.

I think it's because we put our son first. I really do. He is our interest. Whatever each other's politics are, it isn't important. We're not, I guess we're very selfless people. It's about our kids; it's about how they perceive relationships. At the end of the day, kids are a by-product of their environment. We try to provide the most healthy environment we can give them. Everyone plays together.

We did it in the training room, with all the exercises. Each family eats a little differently. Each family had a different take on it of how they were going to do it, but the end result was still the same. When he's at his mom's, this is how they do it, when he's at my place, this is how we do it. It's basically the same thing we learned in the classroom; we just took it home and applied it. We listened to everyone about how this would affect him, and how to keep the negative things at bay. Are we going to have two sets of insulin? Are we going to have dirty needle drops at both houses? We decided we should have a traveling system. As for portioning scales and stuff like that, each family has its own means. Sharps containers and such, each family has its own, including the grandparents. We involved our entire families.

Father #11

Well as our daughter got older she really started doing her own shots. I don't remember exactly when, but I think she's been doing the shots herself for 3-4 years.

Typically, she responds ok. The one thing that I've noticed is that as she's gotten older, how I phrase it and how I deal with it... sometimes she may want a snack. Should I get her something? How do you respond to a 13 year old girl without aggravating her and making her mad.

She's a good kid, so she really doesn't get mad. She gets aggravated, but she understands she knows. We're really pretty fortunate.

She knows, for example, that she needs to check her blood sugar in the morning; I don't really have to remind her. She knows to take her medicine first thing in the morning. Depending on the situation, school, summer, she'll ask for help with determining how much insulin to take.

Father #12

They were wary about going to the pump, but we liked the convenience of it. It has a wireless remote deal. Whenever he eats something now, you just punch in however many carbs it has, and it just gives you the set amount of insulin automatically. It's a lot handier. Since he went on the pump, it's been a pretty good deal. When he and I go out during the day and don't come home until afternoon or evening, I can call Tiffany and tell her what he's eaten. She has it down to a science, and she'll just tell me what he needs to punch in, it goes "beep beep" and we're ready to roll.

Father #13

I: Who takes care of the log book now?

P: We are trying to get him to care of it more now, trying to get him to be more responsible. It usually falls on myself and my wife; we usually make sure it's written down. But he's doing more and more as we go along. With teenagers, it's hard to get them going sometimes.

Here recently we have made it to where if there is a problem, they should call us, mainly if he has a high or abnormal blood sugar. They give us a call, and we let them know what to do. Otherwise he usually takes care of all his insulin administration, and his tests on his own.

Well, you know, normal teenager (chuckles). He doesn't like someone watching him and stuff, but I think that's just a normal teenager.

Oh, just to leave him alone, the normal stuff a teenager would say. It's not nice sometimes, but you deal with it.

I: How do you respond when he does that?

P: Oh, we have punishments, we take stuff away, we ground.

I: At what point did your son start taking on more responsibility for his own treatment?

I would say probably about a year or so before we got the pump. I think that's another reason we decided to get the pump; we started to see where he was becoming more responsible and taking care of himself.

We heard that it was much more convenient to do the pump. Plus, it was a lot better for him. He didn't have to get poked as many times. And it also regulates sugars a lot better, almost like your own body would, like your pancreas would do.

As far as age, he started acting more mature, and so we started trying to put a little more on there to test whether he could be more responsible.

I: So he starts becoming a little more responsible for checking his glucose, doing injections, so you decided to get the pump because of his increased responsibility and the convenience and control around that. Is that right?

P: Yes.

Father #14

For the most part our daughter did it all. We would just monitor and remind her from time to time, and help her with some of the carb counting and that sort of thing. I think at her age we needed to make her as responsible as she could be. That was our goal. She

wanted to continue her social life, sleepovers and such, and we wanted her to be able to do those things without worrying all the time.

Yeah we would monitor her own monitoring. We'd make sure she was giving herself the correct dosage; she gave her own injections and tested everything. And we'd help her keep track of carbs and the logbook.

I: OK, so how did your involvement change when she got the pump?

P: Again, it was an adjustment period. It gave her some more freedom, so we had to make sure that freedom wasn't abused. It was kind of like starting over a little, but not to the same extent.

She became a little lax in recording it in the book because it's recorded in the pump. So she wasn't recording it as much, and we wanted to see that she was doing the testing and such.

Right now we check it the week before the appointment. She's at the age now where we take her to the appointment, but she goes in by herself. They only come to get us if there is something we all need to discuss.

Father #15

I: What about your relationship with your son's biological father? How do you and him interact around parenting?

Its sometimes a little strange because he's not a really responsible person. And one of the things I'm trying to teach the kids is responsibility, so when he does something irresponsible in front of them to me, I usually get upset with him and tell him not to go there.

As he gets older, he can do more himself. If he can't do it himself, we do it.

I: So right after you got home from the hospital, how much was he doing himself?

P: Umm... pretty much none. He wouldn't give shots, but he could check his own blood sugar. The checks in the middle of the night, he wasn't really awake, so Jen would check his blood sugar. The shots we'd do, but during the day he'd check his own blood sugar.

I: OK, so he was in charge of his own sugar, but you did the shots. Has there been much change in that routine since then?

P: We remind him that it's time to check his blood, or we'll ask him if he checked his blood, and then we'll ask him what it is and did he remember to write it down. He's

pretty smart, but he's pretty forgetful. He was much better at tracking his blood sugar early on than he is now. He keeps forgetting to write it down.

The routine around here usually is that one of us will ask in the morning if he checked his blood sugar, just because he is forgetful, then we ask what it is, and then he'll have his breakfast, then the evenings I'll ask if he's checked his blood because Jen's cooking dinner, and then at night I remind him to check it. And I always ask what it is, and then I'll ask if he wrote it down. Every so often I'll check the book myself, but if I've asked him and he has told me what it is, I don't check it. Just every so often I'll ask him to bring me his book and see how it looks. It's probably an area we could be better on, because there will be times I forget to ask or Jen forgets to ask.

Well at first, it was a trust factor. I didn't trust him to do it on his own, didn't want him to hurt himself, so it was just better for me to do it. As he gets older I think he can handle it and do it on his own. We want to teach him to be responsible and independent. But at first we were worried he would hurt himself.

Well there have been a couple of times I thought we were getting lax, and we were trying to let him do his own thing and learn to be responsible. There were a couple of times I thought we were getting a bit careless about stuff, and I got more involved for a while and got onto him about paying attention and taking care of himself because this is something he'll have all his life. If he doesn't pay attention, bad things could happen. But I don't to be the driving force, because he needs to take care of himself eventually.

VITA

Shaun Calix was born in Warner Robins, Georgia on January 9, 1981. Shaun grew up in Birmingham, Alabama and graduated from Shades Valley High School in 1999. He attended the University of Alabama and received his B.S. in Human Development and Family Studies in 2003. He attended the University of Southern Mississippi and received his M.S. in Marriage and Family Therapy in 2005, after which he briefly worked as a substance abuse therapist before beginning his doctoral studies. He completed his doctoral work in Human Development and Family Studies at the University of Missouri in 2013.