

The Experience of Siblings of Children With Type 1 Diabetes

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The pursuit of health is a fundamental value. Chronic illness, therefore, has the potential to profoundly alter one's life experience. Although the effect on the afflicted individual is important, chronic illness is farther-reaching and can significantly alter the experiences of the family and social circles. None of these is more primarily affected than that of the child's immediate family – a topic researched extensively over the past 40 years (Nielsen et al., 2012). It is understood that the presence of illness, especially in a child, is a critical event with the potential to significantly alter family functioning and relationships (Crain, 1966). An early study reported the presence of a chronically ill child in a family results in poor psychosocial functioning and adjustment (Crain, 1966), yet more recent work suggests the potential for a positive impact of chronic illness on family unity, sibling resiliency, and adjustment behaviors (Sleeman, Northam, Crouch, & Cameron, 2010).

According to Crain (1966), the child's specific chronic illness is important because the effect of chronic illness on children and other family members is not universal. Crain (1966) argues that "different types of illness evoke different sets of responses in varied settings" (p. 37), which supports the idea of a difference in family experience and day-to-day management across diseases, such as diabetes, cystic fibrosis, and autism. Based on this concept, it is natural that daily experiences, family relationships, behavioral issues, and family-centered care needs differ for patients with diabetes when com-

Siblings of patients with diabetes mellitus have a unique experience that demands attention from health care providers. The purpose of this article is to explore the sibling experience, identify common fears, and provide the clinician with practical guidance on family-centered care for diabetes management. A comprehensive understanding of factors surrounding sibling adjustment is vital to ensure the best possible outcomes for children and families affected by diabetes.

pared to children with other chronic diseases. Health care providers need to understand the effect of diabetes on siblings to provide comprehensive family-centered care.

Diabetes is a common chronic disease in pediatrics with implications affecting the entire family. Type 1 diabetes mellitus requires complex daily management and frequent monitoring and treatment. There are widespread data that diabetes is quickly becoming one of the most common chronic diseases of childhood. The incidence of type 1 diabetes in children, especially under the age of 5 years, is rapidly increasing in the United States and worldwide (Lipman et al., 2013). According to the Centers for Disease Control and Prevention (CDC) (2011), over 215,000 people in the United States under 20 years have diabetes. From 2002 to 2005, over 15,600 children were diagnosed with type 1 diabetes mellitus annually, with the highest incidence seen in non-Hispanic white youth (CDC, 2011).

Clinicians caring for patients with type 1 diabetes need to be aware of the unique issues affecting the siblings of their patients. Although rates of both type 1 and type 2 diabetes are increasing, this article will focus on type 1 diabetes because of the unique and more intense management needs of this disease.

siblings because its management "requires complex daily monitoring and treatment and has an effect on aspects of family life that are also likely to impact on siblings" (Jackson, Richer, & Edge, 2008, p. 308). The practical and emotional considerations concerning care for diabetes place significant strain on families. As such, diabetes "may affect the adjustment (ability to mentally, socially and physically adapt to stress) of any family members" (Jackson et al., 2008, p. 308). While the diagnosis of diabetes affects all family members, the experience among siblings is particularly varied and requires special attention (Loos & Kelly, 2006). The focus of much of the research in diabetes concerns only the patient, parents, or the entire family, but parental perspectives may differ from that of the siblings (Ferrari, 1984; Wennick & Hallstrom, 2012). Siblings of children with diabetes are at risk of developing emotional disturbances, problem behaviors, low self-esteem, and poor social interactions (Sleeman et al., 2010).

Sources of Sibling Distress

"I was 5 years old when [my older sister] was diagnosed with diabetes. I don't remember much from when I was this age, but I do have vivid memories of the day she was diagnosed. I was in kindergarten at the time when my dad came to get me out of school. I remember being in [my teacher's] class and still to this day could pick out the classroom I was in. When my dad picked me up, he briefly explained that we were going to the hospital to see [my sister]. I remember

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The Impact of Type 1 Diabetes on Families And Siblings

Diabetes has the potential to have a significant impact on families and

having no idea what diabetes was. I did not know if [she] was going to live or die, or anything about the disease. I remember wondering if I could ‘catch’ diabetes” (D.J.C., personal communication, March 23, 2013).

The emotions experienced by this sibling of a patient with diabetes are supported by research. In daily family life, there are numerous sources of distress directly related to diabetes care and management. These can include blood glucose testing, insulin injections, meal times, and episodes of hypoglycemia. A study of siblings of newly diagnosed patients with diabetes found the change to or creation of new family routines is distressing to siblings (Wennick & Huus, 2012). Another study examined parental efforts toward normalizing behaviors, but “found such naturalness to be lost at mealtimes, as eating now included tests and insulin, which drew attention to the illness and reminded the family that the affected child was different” (Wennick & Hallstrom, 2007, p. 304). Instead of being a comforting and enjoyable time of family togetherness, meal times can become stressful, with anxiety regarding blood glucose levels. The type and amount of specific foods available in the home may dramatically change after the diagnosis of diabetes, which may cause resentment among siblings who can no longer eat their favorite or usual foods due to the patient’s diagnosis (Wennick & Hallstrom, 2007). Eating out, which is normally a pleasant and special experience, may become a source of distress due to unknown amounts of carbohydrates in restaurant food and anxiety about correct insulin dosing.

Another area where diabetes affects family functioning concerns the need for frequent blood glucose monitoring and insulin injections. Although the exact number of injections and blood glucose tests vary based on the type of insulin regimen, most patients require blood glucose testing a minimum of four times per day. Patients with poorly controlled diabetes, poor hypoglycemia awareness, or rapid fluctuations in blood glucose levels may need to test more than 10 times daily. Patients need anywhere from two to more than five insulin injections daily. These frequent but necessary events interrupt normal activities, require special equipment, and may cause anxiety in the patient and family members

(Wennick & Huus, 2012).

Episodes of hypoglycemia create fear among patients and their families. In addition to frequent blood glucose testing, patients with diabetes must always have some form of sugar quickly accessible in case of low blood sugar. In extreme cases, parents or siblings may have to put cake icing in the patient’s mouth or give the patient a glucagon injection if he or she has an altered level of consciousness and is unable to eat. The forethought and anticipation required to collect the correct supplies for these events can cause anxiety in patients, siblings, and other family members (Wennick & Hallstrom, 2007).

Factors Influencing Sibling Adjustment

Non-modifiable factors. Multiple factors influence sibling adaptation to a patient’s diagnosis of diabetes. Factors that are not modifiable include age, gender, and time since diagnosis. While some studies find that younger siblings are at increased risk of poor adaptation possibly due to fewer coping mechanisms (Sleeman et al., 2010), others find that older siblings are more aware of changes within the family, which contributes to poorer adjustment (Ferrari, 1984; Jackson et al., 2008). Same-gender siblings to the patient tend to have poorer adjustment as do male siblings (Ferrari, 1984). It has been found that length of time since diagnosis is positively associated with better sibling adjustment and fewer behavior problems (Sleeman et al., 2010). Differences in family size, socioeconomic status, and birth order are not significantly related to adjustment (Jackson et al., 2008).

Modifiable factors. The necessary adjustments of patients and parents to life with diabetes include modifiable factors that significantly impact the sibling’s experiences and adaptation. Higher levels of distress in parents and poor adjustment of the patient are associated with poorer adjustment in siblings. Siblings also have a more negative perception of life with diabetes when the patient is poorly adjusted (Jackson et al., 2008). More stress is evident in all family members, including siblings, during times of poor disease control (Wennick & Hallstrom, 2007).

Specific fears at time of diagnosis. Children’s reaction to their sibling’s diagnosis of diabetes is marked

by sadness, fear, and a sense of vulnerability. In a study of 16 families conducted by Loos and Kelly (2006), the majority of participants had a negative reaction to their sibling’s diagnosis and worried about the unknown. They are upset about the patient’s change in health status and perceive diabetes as an injury to the patient. Siblings lack knowledge about diabetes and that contributes to their fear at the time of diagnosis. Numerous studies have found siblings fear developing diabetes themselves and are concerned for their own health (Loos & Kelly, 2006; Wennick & Hallstrom, 2007, 2012). An unclear understanding of the disease and fear of the unknown magnifies this sense of personal vulnerability.

In addition to being afraid that diabetes is contagious, siblings may be concerned diabetes will ruin or take the patient’s life, a fear that continues beyond the initial adjustment period (Loos & Kelly, 2006). Fear of hypoglycemia persists even a year after diagnosis, and siblings tend not to share these worries with their parents. Instead, they cope with this fear by constantly questioning the patient about how they feel (Wennick & Hallstrom, 2007). Fear of needles used several times daily to test blood glucose and administer insulin is another specific concern that contributes to sibling distress regarding the patient’s disease management (Loos & Kelly, 2006).

Sibling involvement in caregiving. The diagnosis of diabetes changes a sibling’s life in many ways. The patient is usually hospitalized for several days at the time of diagnosis, and the family is apart during this time. One or both parents may be absent from the home to be in the hospital with the patient. Siblings may take on more responsibility at home, and may assume parental roles of caring for the household and other family members (Wennick & Hallstrom, 2007). Siblings feel relief when the patient is discharged because the family is united again and can share the responsibilities in the home (Wennick & Huus, 2012).

Siblings often participate heavily in everyday management of diabetes. In a study of 30 siblings of patients with diabetes, over half were involved in activities, such as gathering supplies, counting carbohydrates, and managing hypoglycemia (Adams, Peveler, Stein, & Dunger, 1991). Sib-

lings provide emotional support, words of encouragement, and often hold the patient's hand or bring them a comfort object during times of blood glucose testing or insulin injections. The majority of the 16 families studied by Loos and Kelly (2006) reported that siblings enjoyed the increased responsibility and participation in care, and this responsibility was associated with higher levels of maturity and a closer bond between siblings.

Behavioral issues. Early investigation into the effect of diabetes on siblings found increased somatic symptoms and higher rates of behavioral problems when compared to siblings of patients without chronic disease or patients with developmental delays (Ferrari, 1984). Other studies show variable results concerning behavior and emotional disturbance of siblings of patients with diabetes when compared to their healthy counterparts. Some siblings of patients with diabetes have significantly lower rates of hyperactivity and peer problems (Sleeman et al., 2010). However, parental ratings and sibling self-assessment of emotional, behavioral, and pro-social behaviors differ. Parents tend to rate siblings as better adjusted, better behaved, and less emotional than siblings' self-ratings, while ratings are consistent for pro-social behaviors and level of peer-related problems. Score differences in some domains support the need for sibling-focused assessments when evaluating family functioning in diabetes, perhaps through direct questioning of siblings rather than reliance on parental report (Sleeman et al., 2010).

Impact on Family Relationships

The diagnosis of diabetes alters family functioning as well as the individual relationships within the family unit. Early research focused on the effect of diabetes on the patient and not other important aspects, such as impact of diabetes on the quality of parent-sibling and patient-sibling relationships (Crain, 1966). More recent studies explore the significant impact of diabetes on these relationships, as well as the relationship between degree of diabetes control and level of family function (Adams et al., 1991; Jackson et al., 2008).

Parent-sibling relationship. The parent-sibling relationship is different

than the parent-patient relationship in diabetes. The mother, usually the most important adult in a child's life for socialization, care-giving, and support, often has a closer relationship with the patient than the siblings because of the patient's dependence on the mother for disease management and daily care (Crain, 1966; Ferrari, 1984). This loss of parental attention can result in feelings of jealousy and neglect by the siblings. Additionally, when the patient's diabetes is poorly managed, feelings of resentment toward the patient may arise because of the resultant increased time demand on the parents (Loos & Kelly, 2006). Siblings feel they again receive a normal level of attention during times of improved diabetes control (Wennick & Hallstrom, 2007).

Patient-sibling relationship. Diabetes has an impact on the patient-sibling relationship, often one of the lengthiest and most significant relationships in a child's life, in both positive and negative ways (Wennick & Huus, 2012). Siblings generally feel increased levels of responsibility for the patient and work to protect the patient from harm and teasing, often strengthening their relationship (Adams et al., 1991; Loos & Kelly, 2006; Wennick & Huus, 2012). The sibling-patient relationship can be strained during times of poor diabetes control or when severe hyperglycemia or hypoglycemia cause physical and emotional instability in the patient (Loos & Kelly, 2006). In addition to feelings of jealousy over increased parental attention, siblings may feel resentful toward the patient for changes in family routine, diet, and privileges, such as later bedtimes and special snacks. Overall, diabetes can bring siblings closer, but often requires the sibling to show increased care and understanding to the patient because of the illness (Adams et al., 1991; Wennick & Hallstrom, 2007).

Clinical Implications

Diabetes has a significant impact on siblings. However, successful adaptation to the disease is possible, and familial cohesiveness can be enhanced through proper diabetes management (Adams et al., 1991; Sleeman et al., 2010). It is important for pediatric nurses and other health care providers to be aware of potential areas of maladjustment for all family mem-

bers, and seek opportunities for intervention and guidance to parents and families throughout their journey with diabetes. Routine follow-up appointments with their nurse practitioner and health care team every three months provide frequent opportunities to monitor family functioning and implement family-centered care.

Need for Education

The relevant literature is clear in the recommendation for more education for siblings of patients with diabetes. Many siblings have a limited understanding of diabetes, and their knowledge is rooted more in observation of the patient and their parents rather than formal education (Adams et al., 1991; Loos & Kelly, 2006; Wennick & Hallstrom, 2007). Siblings desire more education about diabetes so they can better contribute to the patient's care (Adams et al., 1991; Wennick & Hallstrom, 2007). The majority of diabetes education classes and clinic appointments occur during the school day, imposing a significant barrier to sibling participation. Additionally, classes are generally geared toward the patient or parent and lack developmentally appropriate or relevant information for siblings (Wennick & Huus, 2012). Health care providers can overcome these obstacles by offering diabetes education sessions on weeknights or weekends, tailoring the content of specific sessions to the experience of siblings, and researching which interventions are most effective for educating siblings. Inpatient diabetes educators and nurses can include siblings at the time of diagnosis by offering both formal and informal education at the bedside, or in the afternoons and evenings when siblings more often visit patients.

Anticipatory Guidance

It is crucial to provide anticipatory guidance to families to promote positive outcomes for siblings of patients with diabetes. Siblings sense parental stress and tend not to share their personal fears to protect parents from further distress. Parents need to be educated about the most distressing aspects of diabetes for siblings – fear of hypoglycemia, concern for personal health, and uncertainty about the future – and encouraged to question siblings about their specific fears

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to better address these concerns (Adams et al., 1991; Sleeman et al., 2010; Wennick & Huus, 2012). Because diabetes and the degree of control changes over time, these conversations between parents and siblings should occur frequently because new fears and stressors may develop throughout the course of the disease. Additionally, encouraging parents to schedule one-on-one protected time with their children without diabetes can help offset any jealousy or resentment regarding their divided attention.

Because mealtimes can be particularly distressing to the entire family, families should be educated on ways to preserve this time of family togetherness. Parents can include siblings in meal planning, food shopping, and cooking to acknowledge them as an important part of the family and minimize possible resentment from the loss of their favorite meals or a flexible eating schedule. Treating activities of diabetes management, such as blood glucose testing and insulin injections, as normal activities of daily living can minimize the reminder that the patient is different and help preserve a sense of normality (Wennick & Hallstrom, 2007). Parents should be encouraged that whole-family inclusion in diabetes management usually results in improved unity and a sense of togetherness (Adams et al., 1991; Wennick & Huus, 2012). Parents should also be reminded to contact

their nurse practitioner or health care team whenever assistance is needed in diabetes management because poor control negatively impacts all family members (Wennick & Hallstrom, 2007).

Multidisciplinary Collaboration

Social workers are a critical part of the diabetes health care team and excel in evaluating family dynamics. Siblings should be involved in sessions with diabetes social workers as early as possible for the best possible outcomes (Loos & Kelly, 2006). In addition, child life specialists are often members of the multidisciplinary health care team and can offer a comprehensive assessment of family functioning. They are vital to providing age-appropriate teaching and interventions for both patients and siblings to promote disease understanding and management. Social workers, nurses, and nurse practitioners can encourage siblings and help promote a positive outlook on diabetes to foster resiliency among siblings (Wennick & Huus, 2012). Because they are better trained to focus on psychosocial elements of diabetes, social workers can identify situations where siblings may need additional support and individualized therapy. While some factors associated with poor adjustment are not modifiable, such as sibling age, sex, and time

since diagnosis, parents can be educated to improve sensitivity toward and more closely monitor siblings struggling to adapt and function normally. Pediatric nurses and social workers can identify poor patient adjustment, high levels of parental distress, and poor disease control – modifiable factors that influence sibling adaptation – and intervene accordingly. Early identification of impaired patient and parent adjustment is crucial to provide effective interventions, such as individual and family therapy and support, to minimize the burden on siblings.

Sibling Support

Finally, pediatric nurses and nurse practitioners can support siblings by advocating for their presence at clinic appointments and their involvement in social support networks. Siblings need an opportunity to connect with other siblings of patients with diabetes to develop a sense of community and provide mutual support. The opportunity to share personal feelings and hear about other siblings' experiences with diabetes in a non-threatening and supportive environment is therapeutic for siblings (Ferrari, 1984). Sibling support groups and diabetes awareness events also provide a forum where health care providers can edu-

continued on page 305

Children with Type 1 Diabetes

continued from page 282

cate participants about diabetes (Wennick & Huus, 2012). Pediatric nurses and nurse practitioners should be aware of these organizations within the community, and create opportunities for sibling involvement.

The sibling experience highlighted in the introduction to this article illustrates some of the most common fears of siblings of patients with diabetes. Thorough understanding of sibling concerns is a necessity for clinicians to provide excellent family-centered care. Awareness can help pediatric nurses and nurse practitioners execute vigilant and comprehensive assessments of family functioning and sibling adaptation to provide timely and appropriate interventions. ■

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