Being parents of a child who is newly diagnosed with a chronic illness like diabetes is a monumental transition in the lives of families (Hatton, Canam, Thorne, & Hughes, 1995; Lowes, Gregory, & Lyne, 2005). Parents must not only make the necessary adjustments to accommodate the medical management of diabetes, but they must also change their entire world view of their child and their family from that of a “normal” to a family with diabetes (Brink, Miller, & Moltz, 2002; Streisand et al., 2008; Wennick & Hallström, 2006). Nurses can have a seminal role in shaping how a family views their new life with a child with diabetes and how they will cope and adjust to the challenges of day-to-day care.

The Emotional Response to Diabetes

For most parents, the diagnosis of diabetes is unexpected and what is thought to be a visit to the pediatrician for a routine childhood illness becomes a life-changing event. Sadness, anger, guilt, confusion, anxiety, and a new sense of vulnerability are all common reactions to this unexpected news and the process of coming to terms with the diagnosis (Lowes et al., 2005; Streisand et al., 2008; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003; Sullivan-Bolyai, Rosenberg, & Bayard, 2006). Parents have described their experience as similar to being on a “rollercoaster” (Lowes et al., 2005 p. 256) and a time when their world had been “shaken to pieces” (Wennick & Hallström, 2006 p. 375).

In spite of feeling overwhelmed by the sequence of events, parents are expected to digest a significant amount of information in a very short period as they learn the basic survival skills of diabetes care. Many children diagnosed with diabetes spend time in the hospital while their blood glucose levels are stabilized, and families are taught how to monitor blood glucose, administer insulin, recognize and treat hypoglycemia, and count the carbohydrate content of foods (Brink et al., 2002; Swift, 2009).

Fathers have been described as using a strategy of “Suck It up and Do it” to learning basic diabetes management skills while dealing with their experience of shock, sadness, and anger (Sullivan-Bolyai et al., 2006). When parents of infants and toddlers in another study reached the point where they realized that they had “no choice in the matter,” they called upon a number of coping strategies to get them through this challenging time, including resigned acceptance, assertiveness while advocating for their child’s care, looking for a cause, and hoping for a cure (Hatton et al., 1995).

Clearly, many parents are extremely stressed as they attempt to negotiate this trying period. Anger and frustration are frequently directed at health care professionals. The respect, emotional support, and genuine concern offered by providers as parents and children negotiate their way through these uncharted waters are essential (Hatton et al., 1995; Knaff, Breitmayer, Gallo, & Zoeller, 1992). Sensitivity to the degree of disruption that families are experiencing and guidance as they negotiate these challenges support parents and children to begin to make the necessary adjustment that must be made to live with diabetes (Streisand et al., 2008).

The nurturing, understanding, and empathy shown to families by the diabetes team during this period are the foundation for a long-term working relationship.
Tailoring a Diabetes Treatment Program That Fits the Family and Patient

A central concern of families during the period surrounding the diagnosis is whether life will ever be the same for them (Wennick & Hallström, 2006). The “new normal” can most closely resemble the family’s former lifestyle if health care providers take the time to really become familiar with the family and the details of their family life (Lowes et al., 2005; Sullivan-Bolyai, Knafl, Deatrick, & Grey, 2003). Tailoring a diabetes program to the lifestyle of the child/family requires that the health care team know and understand how a family lives and what is important to them.

There are no long-term studies in children that definitively document the benefit of one insulin program over another (Bangstad et al., 2009). However, all diabetes management programs inherently involve a significant degree of lifestyle adjustment. Basal bolus programs are more intensive, requiring multiple injections and meal-to-meal adjustment of insulin doses based on carbohydrate intake and premeal blood sugar readings. More intensive programs allow for more flexibility and potentially a better quality of life. Other programs may be less intensive but are more restrictive in the timing and content of meals and snacks and allow less flexibility. Selection of a specific program is ideally based on family lifestyle. The underlying assumption is that a management program that closely mirrors the family’s day-to-day life is more likely to be followed and will minimize the impact of diabetes on the family’s quality of life (Lombardo, Salzano, Messina, & De Luca, 2005).

When developing a management program with the family, it may be helpful to walk through a 24-hour day and attempt to understand the day-to-day variations in their schedule throughout the week. Many of the normal daily events that were taken for granted can still be done but may require some advanced planning. Helping parents strategize for events like an after-school basketball practice, a soccer game that goes through the usual dinner period, going to the movies and having popcorn, or sleeping at a relative’s home because a parent is working at night is essential to integrate diabetes into their lives. Asking parents what they see as their biggest challenge can help the provider know about problems that only the parent can anticipate.

It is important to instill a sense of balance with the intent to develop a diabetes program based around life rather than a diabetes program based on maximum control at all costs. For example, a teen who wants to sleep late on weekends and who does not want to eat at scheduled times nor follow a specific meal plan would not do well on an NPH/rapid-acting insulin plan that requires following a meal plan at scheduled times, even weekends (Weissberg-Benchall et al., 1995). A finicky toddler whose eating habits are unpredictable would do best with postmeal dosing on basal/bolus regimen. Constructing a regimen with the child and parents that takes into consideration their unique situation can make the difference between a child/family being successful in the diabetes management or feeling burdened, resentful, and failing in their control (Lombardo et al., 2005).

Taking Diabetes Care Home: What Providers Can Do to Help a Family Transition From the Hospital to Home

The transition from hospital to home brings with it new challenges for families managing their child’s diabetes. Parents have described feelings of fear and vulnerability as a result of leaving the hospital support system behind (Hatton et al., 1995). As families attempt to get back into their daily lives, they are faced with the full realization of the impact that diabetes will have on their child and family (Hatton et al., 1995; Lowes et al., 2005).

The stress that parents experience when first caring for a child at home with diabetes places them at risk for anxiety, depression, and other adjustment disorders. Research has shown that almost one third of the stress experienced by parents in first year after diagnosis is associated with parents’ perceived ability to execute the diabetes regimen, the responsibility for diabetes management, and the fears of hypoglycemia. Depression and anxiety may impede parents’ ability to understand and use information and therefore should routinely be assessed during follow-up (Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

The health care team plays a central role in helping families to believe that they are capable of handling this challenge (Sullivan-Bolyai, Deatrick, et al., 2003; Sullivan-Bolyai, Knafl, et al., 2003). Empowering families during the initial period after diagnosis entails helping them to believe in themselves and in their ability to safely care for their child (Hatton et al., 1995). Simple acknowledgement of parents’ efforts helps to build parents’ confidence in their own abilities (Lowes et al., 2005; Sullivan-Bolyai, Deatrick, et al., 2003; Sullivan-Bolyai, Knafl, et al., 2003). A powerful message that families need to hear from the health care team is, “You can do this and we will help you.”

The long-term goal of diabetes care is to enable parents, to the extent that they are capable, to become the primary managers of their child’s diabetes (Brink & Chiarelli, 2004). Families are in the best position to make these day-to-day and meal-to-meal decisions for their child. Ideally, they should be taught to analyze their child’s blood glucose patterns and problem solve with food, activity, and insulin to achieve assigned target goals. The process of providing families with the necessary skills and knowledge to be able to “think like a pancreas” evolves over the course of many months after diagnosis. Parents gradually take on the daily decisions about diabetes management as they gain the necessary skills and knowledge from a multidisciplinary treatment team (Brink & Chiarelli, 2004).

Health care providers empower parents to become experts in their child’s diabetes care by being available when they are
in need of reassurance and by problem solving with them when they are unsure of what to do. Although it might take less time to simply answer parents’ questions, doing so does little to bolster their confidence and ability to problem solve. Rather, talking parents through the challenges by helping them to devise their own answers and solutions to problems will be more effective in helping parents to believe in their own abilities and learn through their own experiences with their child. This is the process of moving a parent from novice to expert in managing their child’s diabetes.

Diabetes: One of Many Chronic Illnesses

Although this article focuses on parents and health care providers managing diabetes, many concepts are applicable to other chronic illnesses. The diagnosis of any chronic illness is bound to have an emotional impact on the patient and family. When providers recognize that parents may react to the stress of the diagnosis with anger, sadness, frustration, and guilt among other emotions, they are able to provide a sympathetic and supportive environment that meets these emotional needs. Through understanding a family’s and patient’s lifestyle, the treatment team can work with the family to develop a plan that will increase their success in managing their chronic condition. Finally, through confidence-building measures and ongoing education, providers can empower parents to move from being novices to being experts in their child’s care.

References