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Family Interaction in Pediatric Diabetes

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Abstract

Adaptation to type 1 diabetes is optimized in the presence of ongoing family support and supervision. Therefore, it is particularly important to understand how family interactions influence adaptation to the illness. The purpose of this paper is to review the current literature on family interaction in youth with type 1 diabetes. Recent advancements in the literature include greater specificity of types of parental involvement, attention to the role of fathers, acknowledgment of the impact of parental distress, increased use of observational methods, and awareness of the impact of culture. Continued parental involvement—particularly monitoring—in the management of diabetes care is important as children transition into adolescence, and the best outcomes are evident when this involvement occurs in a warm, collaborative manner. Parents need support in managing their own distress to maintain this type of involvement.

Keywords

Family relations; Type 1 diabetes mellitus; Adaptation; Psychological

Introduction

The treatment regimen for type 1 diabetes is complex and demanding, requiring frequent blood glucose checks, careful monitoring of diet and exercise patterns, and multiple daily administrations of insulin, as well as managing episodes of hypo- or hyperglycemia [1]. As technology has advanced to offer more options for treatment management (eg, insulin pumps, continuous glucose monitors), the calculations and procedures required for management have become even more complicated. Children and their families are primarily responsible for treatment management, which is often burdensome, and is likely to increase family stress [2]. Because adaptation to type 1 diabetes is optimized by ongoing communication between parents and youth around treatment management, it is particularly important to understand how family interactions influence adaptation to the illness.

Parental Involvement

Although continued involvement of parents in treatment management is associated with better health and psychosocial outcomes in youth with type 1 diabetes [2], researchers and providers acknowledge that the level and type of parental involvement will change with the child's developmental stage. The American Diabetes Association makes specific recommendations for the transfer of responsibility for treatment management, noting that

school-age children (ages 8–11 years) can begin to assume more tasks, such as insulin injections/boluses and blood glucose monitoring, but they continue to need significant assistance and supervision when making management decisions. Adolescents (ages 12 years and older) are able to perform most of the tasks of diabetes management on their own, but they still need help with decision making regarding insulin adjustments [3]. As children reach adolescence, this ongoing need for parental involvement may conflict with the developmental task of increasing autonomy. But several studies have found that when parents give up responsibility for treatment management too early, adolescents have poorer adherence and deteriorating glycemic control [2, 4]. These problems with adherence may result from youth taking on responsibility for diabetes management when they do not have the maturity to handle it [5]. Therefore, parents and other caregivers are encouraged to maintain continued involvement in treatment management throughout adolescence, and to transfer responsibility to adolescents when they demonstrate success in managing diabetes tasks. It is also important to consider that not all involvement is beneficial; over-involvement or intrusive parenting may have a negative impact on adolescents' adaptation [6].

More recently, researchers have begun to examine the types of parental involvement that are most helpful, particularly for adolescents, who are more likely to resist involvement. For example, parental involvement that is perceived as intrusive or “nagging” may result in adolescents becoming resistant, defiant, and noncompliant, or depressed and withdrawn [7]. In fact, a recent multinational study found that adolescent perceptions of parents as overly involved in diabetes care were a stronger predictor of poor glycemic control than age, gender, or insulin treatment regimen [8]. Conversely, adolescents who perceive their mothers as uninvolved in diabetes treatment also have poorer adherence and lower quality of life [9]. Parental involvement that is perceived as collaborative has been associated with the best outcomes, including better glycemic control and quality of life and fewer depressive symptoms [9, 10]. Taken together, these findings suggest that the goal is to encourage communication and collaboration between adolescents and their parents around treatment management.

Investigators have also begun to investigate the effects of parental monitoring as a specific type of parental involvement [10]. Higher levels of parental monitoring, or knowledge of the child's diabetes-specific behavior (eg, how often a child checks his/her blood sugar, how often a child skips an insulin shot or bolus), have been linked with better adherence and glycemic control [10, 11]. It is important to note, however, that the child's willingness to share information (ie, disclosure) allows for increased parental monitoring. For example, if a child is having problems with treatment management, he/she may avoid talking about it or misrepresent information related to diabetes management. Conversely, if the child perceives the parent as warm and accepting, he/she may be more likely to disclose information about diabetes care [12]. Ways to promote disclosure and increase parental monitoring, therefore, may be the target of future research and interventions.

Although the majority of studies on parental involvement have focused on mothers' role as the primary caregiver, researchers have begun to examine the unique role that fathers play in diabetes management. Research suggests that when fathers are highly involved in care for chronically ill children, the decline in treatment adherence typically seen during adolescence no longer occurs [13]. For example, one study found that fathers' (but not mothers') monitoring of diabetes tasks was directly related to glycemic control in adolescents [12]. The effect of paternal monitoring on glycemic control appears to be mediated by improved adherence [11]. It is possible that fathers are not asked to step in and help mothers with diabetes treatment management until glycemic control begins to deteriorate. Further, paternal involvement in treatment management has been associated with better quality of

life in adolescents (age 14 years and older), but not in younger children [13]. There appears to be a distinct, important impact of paternal involvement in diabetes management. However, observational data indicate that fathers of adolescents with diabetes may be less energetic and responsive toward their children than fathers of adolescents without diabetes [14], suggesting fathers may need encouragement to become actively involved before problems arise.

Family Environment

Family functioning has been strongly linked to adjustment in adolescents with type 1 diabetes, including both physiologic and psychosocial functioning [15]. One study found that diabetes-specific measures of family functioning explained 34% of what contributed to glycemic control (compared with only 10% for adherence) [16]. Similarly, diabetes-specific family variables predict 13% to 34% of quality-of-life outcomes [6•]. Research indicates that a family environment that is supportive of diabetes care is associated with better outcomes for youth with diabetes [15]. For example, higher levels of family cohesion and parental acceptance have been related to better adherence to treatment and better glycemic control in youth [12, 17]. Family warmth has also been related to adolescents' quality of life [18, 19]. Recent studies suggest that these benefits of a warm and accepting family environment on adolescents' adaptation may be partially explained by the level of parental monitoring that is present [10, 12].

On the other hand, diabetes-related conflict has been associated with poor psychosocial and physiologic outcomes. In fact, diabetes-specific family conflict has been shown to be a stronger predictor of quality of life in youth with type 1 diabetes than disease severity or intensity of treatment [18, 20]. Further, diabetes-specific family conflict has been associated with poorer adherence [2], as well as elevated depressive symptoms in adolescents [21]. The relationship between family conflict and glycemic control is still unclear. For example, one study found that family conflict was higher when children and adolescents had poor glycemic control [22•]. A longitudinal study, however, demonstrated that maternal reports of family conflict predicted deteriorating glycemic control over time, suggesting that conflict precedes problems with glycemic control [23]. Although longitudinal studies can help us understand the direction of effects, there is likely a bidirectional relationship between these factors, in that deteriorating glycemic control results in greater tension and arguments between youth and parents, increasing stress levels and risk for further deterioration. In addition, the relationship between family conflict and glycemic control seems to be stronger in adolescents than in younger children [16]. Whether family conflict is a cause or consequence of poor glycemic control, it is important to acknowledge its negative effects in youth with diabetes.

Parental Distress

More recently, the impact of parental distress (ie, symptoms of anxiety and depression) on youth with type 1 diabetes and family interactions has been examined. Research indicates that most parents are likely to experience significant distress (eg, symptoms of anxiety and depression) after the child is diagnosed [24]. Recent studies of parents of children with type 1 diabetes found that 23% to 29% of parents scored above the clinical cutoff on a depression questionnaire, which is suggestive of significant depressive symptomatology [22•, 25]. Increases in parents' distress have been related to higher levels of children's distress; maternal depressive symptoms are one of the strongest risk factors for depressive symptoms and poorer quality of life in children [26, 27]. The effects of maternal depression on child depression may be accounted for by family functioning [27]. For example, greater symptoms of maternal depression have been associated with lower levels of observed child-

centered (ie, sensitive) parenting [28]. Parents who are depressed may be less able to provide the warm, accepting environment that is associated with better outcomes in youth with type 1 diabetes.

Similarly, maternal anxiety has been associated with poorer outcomes in adolescents with type 1 diabetes, including externalizing behaviors and poorer glycemic control [26, 29]. It is possible that anxiety results in mothers taking on responsibility for the majority of their children's treatment management, conflicting with adolescents' developing needs for autonomy and independence, and resulting in withdrawn or defiant behavior [29]. For example, a recent study found that greater symptoms of parental anxiety were related to higher levels of diabetes-specific family conflict [22•]. Parents who are anxious about an adolescent's deteriorating glycemic control may also be more likely to engage in intrusive parenting behaviors such as nagging, leading to increased parent-child conflict [22•]. Although more research is needed to better understand the relationship between parental distress and family interaction, the existing evidence supports the need to begin helping caregivers cope more effectively with the stress of treatment management to reduce their psychological distress [30].

Observational Studies of Family Interactions

The majority of research on family functioning in children with type 1 diabetes has relied on mothers', and occasionally children's, reports of parenting and family environment [31], but observational studies may shed light on specific aspects of parent-child interactions that influence adaptation to diabetes. For example, one study that coded observed behavior in youth and their parents during a diabetes-related task found that higher levels of observed emotional support, acceptance, and conflict resolution, and lower levels of observed parent anger and sadness were related to better glycemic control [32]. Another study found that higher levels of mothers' observed hostility and lower levels of child-centered behavior and positive reinforcement were related to poorer psychosocial adjustment and poorer glycemic control in adolescents [28]. Similarly, a higher frequency of negative parent-child interactions has been related to lower quality of life [6•]. More specifically, an observational study of mealtimes found that families of young children with type 1 diabetes exhibited poorer family communication and overall family functioning than a control sample [33]. Other researchers have used observed parent-child interactions as an outcome measure in intervention studies of adolescents and their parents, showing that improvements in parent-child communication were associated with better adherence and adjustment to diabetes and improved glycemic control [34]. Continued use of observational methods will help to determine the impact of specific parenting behaviors—particularly those that may be related to the stress of treatment management—on adaptation in youth with type 1 diabetes, highlighting the behaviors that could be targeted for interventions.

Family-Based Interventions

Given the importance of family in diabetes management, multidisciplinary collaborations among clinicians and researchers have resulted in the development of family-based interventions to improve parent-child communication and collaboration around treatment management. For example, Wysocki et al. [34, 35] have shown that the Behavioral Family Systems Therapy for Diabetes, which targets family communication and problem solving, improved glycemic control and adherence and reduced family conflict. Coping Skills Training interventions developed by Grey et al. [36, 37•] have also shown improvement in glycemic control and quality of life by teaching youth and their parents strategies to manage common diabetes-related stressors. Family-based interventions designed to reduce the time and cost required in more intensive interventions have also had positive effects; Anderson et

al. [38] reported that a brief, in-office intervention to promote parent–child teamwork improved glycemic control and parental involvement. Overall, previous studies aimed at improving adherence and glycemic control have shown modest to moderate effects on health outcomes, and many were time intensive and expensive [39]. Thus, novel approaches for family-based interventions in youth with type 1 diabetes are still needed.

Special Considerations for Families of Young Children

Although type 1 diabetes is most often diagnosed in adolescence, the incidence in younger children is rising [40], and young children may present unique challenges for family management of type 1 diabetes. Because young children are less likely to be aware of or able to communicate signs of hypoglycemia, parents report high levels of parenting stress related to fears of hypoglycemia [41, 42]. These fears may prompt some parents to engage in diabetes management behaviors to prevent hypoglycemia, which could result in poorer glycemic control [41]. Parental fears of hypoglycemia may also present challenges related to mealtimes. For example, an observational study found that parents of children with type 1 diabetes were more likely to command children to eat than parents of control children, and these coercive parenting behaviors were associated with poorer glycemic control [43]. Although more research in this population is needed, these studies suggest areas for interventions to meet the specific needs of families of young children with type 1 diabetes.

The Role of Race/Ethnicity

Studies suggest that minority youth with type 1 diabetes are at greater risk for poor glycemic control than white youth [19, 44], but the mechanism of risk is not well understood. Although there is some evidence that these differences are accounted for by the effects of socioeconomic status and family structure (ie, single vs two-parent household) [45], it is likely that cultural differences in parenting also contribute to differences in parental involvement that might influence glycemic control. Hispanic culture, for example, is more likely to emphasize the needs of the family than Anglo-American culture, which promotes the development of autonomy during adolescence. In line with this, studies have found that Hispanic youth are less independent in managing their care than white non-Hispanic youth [46], and Hispanic youth have better adherence when they have greater family support and when parents had greater responsibility for diabetes management [47•]. Another study found that parents of minority youth (primarily African American) demonstrated significantly lower levels of monitoring adolescents' diabetes management than parents of white youth [48]. Therefore, race/ethnicity and the impact of culture are important to consider when studying the effects of family on adaptation to type 1 diabetes.

Conclusions

Type 1 diabetes is unique in that it requires the child and his/her family to be responsible for the majority of disease management, and this intensive level of responsibility is likely to increase family stress and conflict, particularly as children reach adolescence [2]. As such, continued research is needed to find ways to support children with type 1 diabetes and their families to cope with the challenges and stress of the illness and treatment regimen to promote the best adjustment to the illness, including both physiologic (ie, glycemic control) and psychosocial adjustment (ie, quality of life). Recent advancements in the literature include greater specificity of types of parental involvement, attention to the role of fathers, acknowledgement of the impact of parental distress, increased use of observational methods, and awareness of the impact of culture. Continued parental involvement—particularly monitoring of diabetes management—is important as children transition into adolescence, and the best outcomes are evident when this involvement occurs in a warm, collaborative

manner. Parents may need support in managing their own distress to maintain this type of involvement.

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