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Autonomy and insulin in adolescents with type 1 diabetes

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Research concerning adolescent development and diabetes that considers the impact of various new treatment modalities has valuable implications for the development of appropriate education and intervention strategies for this population. The recommendation for intensive insulin therapy in type 1 diabetes (T1D) in adolescence has resulted in a number of studies demonstrating the medical benefits of the various modalities of such treatment (1–3). However, fewer studies explore the psychosocial impact of this intensive therapy on adolescents and families (4). In this article, we examine the research on autonomy in adolescents with T1D and consider the ‘pump vs. injections’ debate from a developmental perspective. The final section of this article includes general recommendations and pump-specific considerations for diabetes health-care providers to encourage safe autonomy development in adolescents with T1D.

T1D is a genetic disease of the immune system characterized by pancreatic beta cell destruction and a consequent lack of insulin. Recent data suggest that 15 000 youth in the USA are diagnosed with T1D each year, and the incidence rate is highest in children aged 10–14 (5). The recommendations by the American Diabetes Association (ADA) support the use of an intensive insulin regimen that involves a ‘basal/bolus’ pattern of insulin administration to maintain blood glucose levels as close to normal as possible, with a target hemoglobin A1c (HbA1c) of less than 7.5% for adolescents (aged 13–19) (6). This pattern can be achieved by either multiple daily injections (MDI), which involve a daily injection of a long-acting (basal) insulin and injections of rapid-acting (bolus) insulin to cover meals and to correct high-blood sugars, or continuous subcutaneous insulin infusion (CSII), in which basal insulin is delivered by the constant infusion of small amounts of rapid-acting insulin through an insulin pump (6–8). Both types of basal/bolus therapy require frequent blood glucose monitoring (at least four/day) and tracking carbohydrate intake and exercise in order to make insulin dosing decisions (9). The ADA also emphasizes the need for developmentally appropriate interventions that include adolescents and their caregivers (6).

Developing with diabetes

Clinicians treating adolescents with T1D must recognize that progressing through adolescence and having diabetes are individually difficult processes that are inexorably linked and complicated by one another. The life stage of adolescence involves recurring themes of identity, achievement, autonomy, and intimacy (10). Adolescents continuously meet successive challenges in each of these areas, while faced with important decisions that

involve school, sexuality, substance abuse, health behaviors, societal attitudes, future life options, and self-worth (10). Adolescents with chronic diseases like diabetes face additional and unique challenges when acknowledging or adapting to the disease directly conflicts with the normative tasks of adolescence (10). Chronic illnesses are associated with increased school absences, disease-related fatigue, pain, and medication regimens, as well as altered methods of parenting and social interactions that may interfere with the developmental tasks of adolescence (11). Indeed, adolescents describe the demands of diabetes and adolescence as being integrally linked (12). These conflicting stressors may result in conscious adolescent behaviors (e.g., choosing not to bolus at a social event) that a health-care provider might mistakenly view as simple non-compliance (12).

Just as clinicians monitor growth and the presence of physical manifestations of puberty, they must be cognizant of the cognitive changes taking place. Adolescence is marked by a progression in the ability to generate options, to view situations from multiple perspectives at the same time, to acknowledge and predict long-term consequences, and to evaluate the reliability and importance of information (10). Although these advances in cognition might theoretically render an adolescent increasingly fit for diabetes self-management, adolescents' social cognitive skills are usually less developed than their academic cognitive skills (10). For example, the 'imaginary audience', or an idea that others are constantly watching and evaluating, might create an acute self-consciousness of diabetes management tasks performed in social settings (13). Furthermore, the 'personal fable', the notion that one is unique and invulnerable, might diminish an adolescent's motivation for self-management efforts that would prevent complications later in life (13). Furthermore, adolescents' anticipation of negative peer reactions to their diabetes care has been associated with higher levels of diabetes-related stress, problems with adherence in social situations, and poorer metabolic control (14). Indeed, the interaction of biological and psychological developmental factors often causes problems maintaining metabolic control; surging growth hormone levels and associated insulin resistance (15) require increased management efforts that distinguish adolescents from their peers at the very time when they feel their differences most acutely (14). Furthermore, adolescents may feel least vulnerable to the consequences of suboptimal management and poor control (13).

While having diabetes can positively or negatively affect adolescents' achievement of various developmental tasks (11), its influence is perhaps felt most acutely in the struggle to establish and maintain autonomy. The following sections of this article will examine autonomy development and the importance of parental involvement in treatment management.

Autonomy and diabetes

For the purpose of this article, autonomy is defined as 'responsible independence'; its development begins at birth, continues throughout the life span, and is especially central to adolescence (16, p. 97). Few researchers have investigated the concept of autonomy in adolescents with diabetes (17), but one study found that adolescents with and without diabetes did not differ in their perceived or desired autonomy from their parents over a period of four years (11). Another qualitative descriptive study found that the cognitive, behavioral, and emotional components of autonomy development were similar in healthy adolescents and adolescents with diabetes, but the group with diabetes was advanced in two aspects of behavioral autonomy, recreational activity, and self-care (18). Finally, another study found that increased 'independent decision-making', but not 'independent functioning', in daily diabetes management was associated with improved metabolic control (17). The results from these studies suggest that adolescents with T1D experience autonomy

development similar to adolescents without T1D, and that autonomy in making diabetes-related decisions may be related to metabolic control.

Parental involvement

Although few researchers have investigated the concept of autonomy development specifically in adolescents with T1D, a number of studies have examined the division of responsibility of diabetes management tasks between parent and child. Studies indicate that greater parental involvement in adolescent diabetes management is associated with better metabolic control (19, 20) and that shared responsibilities are associated with better adolescent psychological health and self-care behavior (21). Still, findings suggest that parents frequently transfer the responsibility of diabetes management at too young age (20), and poor adherence during adolescence may result from youth taking on self-care levels that are disproportionate to their psychological maturation (22). Mothers of adolescents with diabetes have cited their child's physical maturity and increased autonomy as reasons for transferring disease management responsibilities; they also referenced external pressures from others and the desire to avoid hassles and conflicts (20). The current ADA standards of care for children and adolescents recommend a gradual transition toward independence in management during middle and high schools, emphasizing that adult supervision remains important throughout the transition (6).

Although parental involvement might improve metabolic control, it also holds the potential to hinder an adolescent's development; controlling and rigidly organized families can inhibit the development of an adolescent's broader autonomy (17, 23). Furthermore, conflicts related to adolescent autonomy may decrease adherence to diabetes treatment regimens and compromise metabolic control (24–26). Parental involvement that is perceived as supportive and collaborative has been associated with better outcomes, including better adherence and metabolic control (27, 28). In the next section of this article, we will examine metabolic control, quality of life, and autonomy development in relation to two different intensive insulin therapy treatment options and consider how an adolescent's autonomy development might influence, or be influenced by, treatment choice and intervention strategies.

Comparing the pump to CSII

There is some evidence that CSII, or the insulin pump, as compared with MDI, may improve metabolic control and hypoglycemia (29), but large, randomized clinical trials are still needed to consider insulin pump therapy first line for all adolescents with T1D (1). It is also important to note that physicians may be more likely to recommend pump therapy for adolescents who have better metabolic control. Therefore, it is important for providers to look beyond metabolic control and consider the impact of differing modalities on quality of life, adolescent autonomy level, and self-management behaviors in their treatment decisions.

Quality of life

Many of the studies concerning quality of life and diabetes treatment regimens predate the long-acting insulins glargine and detemir, and thus preclude conclusions regarding the psychosocial benefits of basal/bolus MDI vs. CSII (30). In addition, many of the studies concerning quality of life effects of pediatric pump use have focused on very young children or have not specifically examined adolescents (31). Several studies have suggested that no significant differences exist in the diabetes-specific quality of life of CSII and MDI users (3, 32–35), but others have found that the pump does, in fact, increase the quality of life in adolescents (36, 37). Other research indicates that the *type* of insulin used in MDI (e.g., NPH vs. basal/bolus with glargine) (30), but not the *number* of daily injections (36), affects the quality of life improvements seen with pump initiation. A recent study indicated that

improvements in quality of life in children who transitioned to pump therapy that were predicted by psychosocial, medical (including prepump regimen), and demographic characteristics (38). Perhaps the most convincing argument in the pump vs. MDI quality of life debate is the fact that the majority of participants in the studies reviewed chose to remain on or switch to the pump after the study completion, even in studies where the pump showed no benefit over MDI in terms of metabolic control (1).

Autonomy and treatment modality

Although the benefits of parental involvement in diabetes management have been established and the patterns of management transition preliminarily explored (22), the current literature has not explicitly examined the autonomy or the division of responsibility in relation to treatment modality. Potential benefits of CSII include more flexibility in diet and schedule, fewer reminders from parents, reduced feelings of dependency, and ease of insulin administration and dose adjustments (35, 37, 39). Furthermore, the pump has been shown to reduce the degree of limitation that families experience related to an adolescent's general health and well-being (35). However, successful use of CSII requires the additional tasks of preparing the insulin reservoir and tubing, inserting the pump site itself, programming basal rates and bolus settings, and entering blood glucose readings into the pump. In one study, parents and clinicians reported that CSII-related skills were more difficult for adolescents to attain than MDI-related skills; according to parental report, children attained skill mastery in only *half* of the CSII tasks between the ages of 11 and 13 (40). In fact, self-management has been the most frequently cited difficulty of CSII use by parents and adolescents (4). On the other hand, technologically savvy adolescents might be more comfortable than their parents with the actual pump device (40). CSII has also been shown to increase an adolescent's sense of control and independence (39) and to improve individual diabetes self-efficacy regardless of the intensity of the prior injection regimen (36). Furthermore, parents perceive their children as better able to independently manage their diabetes after transitioning to the pump (37). Although the pump provides the tools for insulin administration in a compact and convenient form that might increase an adolescent's level of responsibility and independence, it is important to remember that its insertion does not render an adolescent suddenly capable of autonomous diabetes management.

Recommendations for the transition of responsibility

This article highlights the ways that diabetes control is associated with parental involvement and adolescent autonomy. Certainly, shared responsibility and continued parental supervision in adolescent diabetes management are ideal; however, this may be difficult for parents when adolescents are developmentally inclined to resist such efforts, resulting in increased family conflict and compromised diabetes control. Providers whose patients are using or initiating pump therapy face a unique and paradoxical task. They must effectively encourage parental involvement while prescribing a treatment that has been shown to increase adolescent autonomy in diabetes management. The final section of this article includes general recommendations and pump-specific considerations for diabetes health-care providers to encourage safe autonomy development in adolescents with T1D.

Consistently inquire about division of diabetes responsibilities and quality of life—Autonomy is an important aspect of diabetes self-management and deserves explicit attention in discussions between adolescent, parent, and provider (17). By assessing parental-adolescent division of diabetes management responsibilities at each visit, providers can offer the most appropriate anticipatory guidance regarding the transfer of responsibility for diabetes-related tasks (41). Continued parental involvement and supervision of diabetes management should be stressed and a collaborative relationship encouraged (27), reminding

families of the improved metabolic control (19), psychological health, and self-care behaviors (21) associated with continued parental supervision. The optimal transition is facilitated by a team approach (24) and occurs in response to a child's success in the performance of management tasks and his or her autonomy level (19). In addition, periodic monitoring and discussion of health-related quality of life may have positive effects on the psychosocial well-being of adolescents with T1D (42). Adolescents perceive clinicians who inquire about quality of life to be supportive and reportedly appreciate the opportunities for shared decision-making that such inquiries provided (42). Thus, recommendations and attempts to increase the quality of life should target on child, parent, and family adjustment, rather than focussing only on disease-related outcomes such as HbA1c (34).

Provide anticipatory guidance and foster responsible decision-making skills

—Beginning at early adolescence, providers can counsel parents and children about the importance of parental involvement in diabetes management in the upcoming years. These conversations will ideally acknowledge that adolescents, in keeping with their developmental stage and regardless of their treatment modality, will at times resist parental supervisory measures. As an adolescent's increased independent decision-making, and not independent functioning, has been linked to metabolic control (17), patient education should emphasize decision-making skills unless a deficiency in a technical skill (e.g., pump site changes and injection technique) is identified. Providers can explain that some adolescents find self-management particularly challenging in social settings (4, 12, 14) and provide adolescents with concrete examples of problematic situations in a non-judgmental manner (e.g., 'some kids your age say it is hard to remember to bolus at lunchtime') to develop solutions that are more likely to be appropriate, comprehensive, and effective. Interviewing an adolescent alone for a portion of each visit to address topics such as substance abuse and sexual activity is similarly important; in this setting, providers can again give developmentally appropriate examples (e.g., managing insulin with alcohol intake and what to do with the pump in intimate settings) to trigger discussion about topics an adolescent may not have identified as problematic or might be embarrassed to breach on their own.

Target missed boluses in social settings—Much of the decline in metabolic control in adolescents has been attributed to missed boluses (42). The effects of these missed boluses on metabolic control are substantial; four missed meal boluses per week can result in a 1% increase in HbA1c (43, 44). Furthermore, such insulin omissions can become a point of contention over parent-child negotiations of responsibility. One study of adolescents on pump therapy reported that 10% of subjects missed mealtime boluses (45), and it is likely that many missed boluses occur in social settings (4). The most commonly reported reasons for missing pump boluses are related to emotional functioning (e.g., a failure to accept disease or shame over revealing disease at school) (45). MDI users are similarly faced with the challenge of the public bolus – though an adolescent's peers may actually notice, inquire, and sometimes tease him or her about diabetes-related tasks or equipment, adolescents are more likely to feel the presence of *any* audience more acutely, possibly compromising their disease management efforts. In order to encourage improvements in bolus habits, providers need to inquire about missed boluses to determine whether these are because of underlying difficulties or misunderstandings regarding pump function, carbohydrate counting, or the concept of basal/bolus regimens present, or whether missed boluses result primarily from social concerns. For example, given the adolescent's particular situation, would he or she be more likely to bolus with the pump or with an injection? In general, bolusing with the pump is quicker, requires fewer tools, and might result in fewer trips to the nurse's office, but in cases when adolescents struggle with pump boluses in a social context, the possibility of a 'pump break' or increased nurse and parental supervision of bolusing could be considered. Careful assessment and counseling that include

modality-specific strategies for bolusing in social settings are essential to facilitating an adolescent's autonomy development.

Reduce the incidence of severe lows—An adolescent struggling to achieve autonomy may experience a major setback in the form of a severe low-blood sugar. Such an incident of hypoglycemia may call into question his or her ability to self-care and could result in renegotiations of self-management responsibilities (35). Moreover, frequent low-blood sugars may limit the strictness of an insulin regimen and result in poorer metabolic control (46). Regardless of treatment regimen, careful education regarding the duration of insulin action and reduced insulin requirements related to low-premeal glucose readings and/or planned activity can minimize an adolescent's risk for hypoglycemic events. In addition, it is important for health providers not to blame the adolescent for episodes of hypoglycemia, but to acknowledge that they are a common occurrence when the goal is tight control. The pump simplifies strategies to reduce hypoglycemia and provides additional strategies not available with MDI use. For example, adolescents on the pump can safely and effectively reduce the risk of hypoglycemia during exercise by temporarily suspending basal rates or disconnecting their pump (47). Nighttime lows can be avoided after intense exercise by adjusting overnight basal rates (48). Decreased rates of hypoglycemia related to sports and exercise may allow adolescents with diabetes to choose activities with less restriction and thus lessen the impact of diabetes on their general autonomy. Finally, insulin pumps consider 'insulin on board', (i.e., the remaining duration of action of insulin already infused) in dose calculations; recent generation pumps will automatically reduce a bolus when a prior bolus has been administered within a specified period of time (49). This feature helps to prevent the phenomenon of insulin stacking (49) and the possibility of a hypoglycemic episode. Careful explanation and use of this feature may help to ease the mind of a parent who is worried about the adolescent who self-administers insulin.

Routinely assess responsibility through pump memory—Pump memory serves as a useful tool in assessing and negotiating the safe development of autonomy in adolescence. Although adolescents (and parents) often forget to record blood glucose readings, the pump provides data independent of the adolescent's willingness to record or the accuracy of his or her recall. In addition, these data are not subject to the possible falsification of numbers, which may complicate the assessment of adherence in MDI therapy. By carefully training parents in how to navigate the pump's history or delivery summary features, providers can help families to identify methods of pump review that fit their lifestyle. For example, the dyad might sit down and scroll through the pump history together, a parent could 'borrow' the adolescent's pump for review during a time when the pump is removed (e.g., shower), or a computer printout of delivery summaries could be reviewed by parents. Of course, some adolescents might consider such monitoring an infringement upon their independence or an indication of a lack of parental trust. By presenting pump review as a routine part of pump therapy, providers may help to avoid parent-child conflicts over this topic. For adolescents transitioning to the pump, providers can explain that, in exchange for greater flexibility and increased responsibility for insulin administration, they must demonstrate their capability of consistent pump management skills before parental supervision can be responsibly tapered. Pump review by a parent or caregiver might occur prior to each bolus but then be slowly tapered to every second or third day, as patients begin to take on responsibility for treatment management (45). Of course, the memory's utility is dependent on the motivation of the parent to review it, the willingness of the adolescent to have it reviewed, and the careful advice of the provider that encourages its practice. Pump memory facilitates the sharing of reliable and unbiased information between adolescent, parent, and provider at clinic visits and optimizes dose adjustment and other interventions.

Conclusion

Adolescent development is important to consider when making decisions about treatment type, but it has received little attention in the literature. Moreover, the ADA's recommendation for a gradual transition of responsibility from parent to child is of extreme clinical relevance but is sometimes trumped by a focus on metabolic control and treatment modality comparisons. As previously discussed, studies that have revealed small and inconsistent differences in metabolic outcomes of different intensive insulin treatment modalities are far less striking than those that have illuminated the significant *negative* metabolic impact of increasing adolescent autonomy and/or suboptimal self-management behaviors (e.g., missed boluses). Thus, perhaps the battle for metabolic control in adolescence is best fought by heightening our focus on adolescent diabetes self-management and improving the ways in which families transfer diabetes management responsibilities from parent to child. Health-care providers can use the recommendations outlined in this article to help facilitate safe autonomy development in adolescent diabetes management. More studies are needed to understand the effects of treatment modality on adolescent responsibility for diabetes management and to explore the efficacy of interventions encouraging parental supervision and shared diabetes responsibilities in families of adolescents using both MDI and CSII.

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