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The Role of Parent Self-Regulation in Youth Type 1 Diabetes Management

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Abstract

Purpose of review: Youth with strong self-regulation (SR), or the ability to manage thoughts, emotions, and behaviors, engage in more effective type 1 diabetes (T1D) management. However, while parent support and engagement are critical to ensuring positive youth T1D outcomes, it is rarely considered that parents' SR may also influence youth T1D management. If this is the case, novel interventions to improve parents' SR or ensure adequate support for parents with SR challenges offer great potential to improve family functioning and youth T1D management.

Recent findings: Theoretical and preliminary empirical evidence suggests that parental SR impacts family processes that support youth T1D treatment regimen adherence. Further, parent and youth SR likely interact, with high parent SR enhancing the positive effects of high youth SR or compensating for low youth SR.

Summary: Continued research is needed to better understand the ways in which parent SR matters to youth T1D management, and identify how to support improvements in T1D management among families of parents with low SR.

Keywords

Pediatric Type 1 Diabetes; Self-Regulation; Parenting; Executive Function

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Introduction

The attention, planning, and decision making required for optimal management of type 1 diabetes (T1D) is demanding for many youth and their families. To avoid the complications of T1D, youth (i.e., children and adolescents birth through age 18) and their parents are advised to follow complex treatment regimens that include monitoring blood glucose, calculating and administering insulin doses, tracking carbohydrate intake, and managing the stress associated with adhering to these regimens.[1] While diabetes technology and devices, including continuous glucose monitors (CGM) and insulin pumps, facilitates some of these tasks, technologies do not eliminate self-management demands and in many cases, introduce different tasks and stressors (e.g., responding to CGM alerts about glucose variations).[2–4] In part because of these daily demands of T1D management, the majority of children and adolescents with T1D are not able to achieve optimal glycemic control.[5]

Self-regulation (SR) refers to one's ability to manage thoughts, emotions, and behaviors to achieve a desired outcome.[6] While different disciplines use varying terminology to describe SR and the component processes of SR, we conceptualize SR as encompassing *executive functions*, or the cognitive processes that support organizing, focusing, delaying gratification, and problem-solving; the ability to *regulate emotions*, particularly when encountering stressors and other challenges; and *future orientation*, or an individual's propensity to anticipate and value future goals, and engage in behaviors to promote these goals.[7]

Recent reviews have highlighted associations of small to moderate magnitude between SR, T1D self-management, and glycemic control among youth.[8, 9] Further, youth with Attention Deficit/Hyperactivity Disorder (ADHD), a condition exemplified by SR difficulties, have been found to have poorer glycemic control.[10] SR likely supports T1D management through several different mechanisms. First, poor executive function can make it difficult for youth to remember steps of complex T1D routines, avoid having T1D routines disrupted by stressful life events, pause a more engaging activity to check their blood glucose, or resist food choices that may make estimating insulin needs more difficult.[11] Youth with weaker emotion regulation may be less able to attend to their T1D during upsetting events or experience more distress around daily diabetes-related stressors (e.g., frustration with out of range glucoses or fear of hypoglycemia) due to their limited ability to draw on self-calming skills.[12, 13] Stress may also lead youth with poor emotion regulation and limited future orientation to engage in behaviors that temporarily reduce stress but make glycemic control difficult, such as binge eating or avoiding care altogether.[14] Finally, limited future orientation may hamper youths' ability to visualize and value the long-term benefits of T1D adherence, resulting in less motivation to engage in daily T1D self-management tasks.[11]

The Role of Parent SR in Family and Child Health

Nearly all research examining links among SR, health behavior, and health outcomes has focused on the impacts of an individual's own SR. What is rarely considered, however, is

that for youth, their parents' SR may play an equal or even more important role in promoting positive social, emotional, and physical development.[15, 16] Crandall et al.[17] provide a useful framework for considering the broad influence of parents' SR on children's development. Drawing from the developmental psychology literature, these authors proposed that strong parent SR contributes to parents' ability to be less emotionally reactive to situations and regulate behavioral outcomes when affective arousal occurs. This regulation has direct and meaningful impacts on parenting behaviors including the ability to implement family routines, scaffold child learning, demonstrate sensitivity, tolerate frustration, and model effective emotion regulation. These parenting behaviors both directly promote children's positive health and development from infancy through adolescence, and indirectly improve children's health and development via strengthening children's own SR.

Conceptual Model of Role of Parent SR in Pediatric T1D

Guided by Crandall, et al.,[17] we have developed a T1D-specific conceptual model demonstrating the hypothesized associations between parent SR, youth SR, diabetes-supportive family processes, youth treatment regimen adherence, and youth glycemic control (Figure 1). Specifically, parent SR, comprised of executive function, emotion regulation, and future orientation, is hypothesized to support youth T1D treatment regimen adherence through two diabetes-supportive family processes: adaptive family cooperation and parent participation in children's diabetes management (Path 1). Aspects of adaptive family cooperation central to supporting youth treatment regimen adherence include minimizing parent-child conflict, engaging in collaborative problem solving, and facilitating supportive communication. These processes rely on strong parent SR. For example, strong executive function skills support parents' establishment of family diabetes routines and provide flexibility of thinking to identify alternative solutions when behaviors, such as checking blood glucose during a sleepover, feel unacceptable to children. Parents with strong emotion regulation may be less likely to get frustrated with their children when they miss a diabetes management task; for example, checking their blood glucose before a sporting event. Finally, strong future orientation allows parents to recognize that the work of engaging in supportive and responsive communication with their children is worth investing in because it will reduce the long-term risk of their children having adverse T1D-related outcomes.

Parents' SR also supports direct participation in children's T1D management. This includes implementing diabetes-related tasks (e.g., checking blood glucose, counting carbohydrates, calculating/administering insulin doses), scaffolding children's learning of these tasks, and monitoring children's engagement in these tasks. We hypothesize that these tasks heavily rely on executive function skills such as planning, organization, problem solving, and mentally updating information. Emotion regulation is also likely important to parent engagement in these activities as the ability to stay calm in what can be very stressful situations, for example a child experiencing hypoglycemia, aids parents' successful completion of tasks.

It is important to consider that the pathway between parent SR and diabetes-supportive family processes is likely bidirectional. Some have hypothesized that SR is like a muscle,

which with extensive use and stress can be depleted.[18] Family conflicts around T1D management and the vigilance of monitoring youth T1D may weaken parents' SR, further weakening diabetes-supportive family processes, interfering with youth treatment regimen adherence and ultimately, leading to poor youth glycemic control and adverse T1D events.

Parent SR also indirectly supports youth treatment regimen adherence via youth SR (Path 2). SR is intergenerationally transmitted through biological and socioenvironmental mechanisms. This includes moderate to strong genetic heritability of executive function and emotion regulation.[19–21] Additionally, as discussed earlier, SR allows parents to create responsive, low-stress environments for children, scaffolding children's SR development. [22] Increases in youth SR, supported by parent SR, further contribute to adaptive family cooperation and effective, low-conflict, parent participation in T1D management, which support greater youth treatment regimen adherence.[23, 9, 8] Alternatively, when parents have weaker SR, their children are also likely to have weaker SR because of these genetic and socioenvironmental mechanisms. Similar to how stressful family processes may weaken parents' SR, youth dysregulation may burden parents' already weak SR, again triggering a cascade of suboptimal family coordination, which places youth at high risk for acute adverse T1D events.

Finally, parent SR is hypothesized to modify the impacts of youth SR on diabetes-supportive family processes (Path 3). This path reflects the concept of "load sharing," where in close relationships, stronger SR among one family member can enhance another family member's goal-directed behaviors.[24, 25] For example, parents with strong emotion regulation may be better able to support their distressed or frustrated child such that the child's dysregulation does not contribute to increased diabetes-related family conflict or interfere with parents' scaffolding of diabetes management. Conversely, in families where both youth and parents experience poor SR, there may be no one able to "pick up the slack" with regard to complex diabetes-related tasks, and families may experience a cycle in which low parent and youth SR amplify family conflict about T1D, leading to suboptimal treatment regimen adherence and out of range glucose levels. This stress of poor youth glycemic control may then weaken parent and youth SR further, pushing family members to the boundaries of their capacity to self-regulate, increasing family stress and creating greater barriers to collaborative family diabetes management.

It is likely that the mechanisms by which parental SR impacts child T1D management encompass different activities and processes as children age. For young children, parents are solely responsible for children's care and coordination of daily T1D tasks. Therefore, one would expect that parents' executive function capacity strongly predicts how effectively children's T1D is managed. These parents also shoulder the psychological and emotional tasks of coping with stress, maintaining self-care to reduce risk of burnout, and effectively parenting their children through appropriate developmental events such as limit testing and picky eating.[26] Stronger SR, and particularly capacity to regulate emotions, can help parents navigate these tasks and more effectively cope with the distress that often comes with these responsibilities.[27, 28]

Parenting school-aged children and adolescents with T1D involves challenges including supporting youth in developing diabetes self-management skills, negotiating responsibility for treatment regimens, and minimizing family conflict. During the elementary school years, parents continue to be very involved in conducting daily diabetes management tasks. Therefore, parent SR deficits that interfere with T1D management for young children likely also affect school-aged children. Further, school-aged children often become increasingly aware of social norms and how T1D can make them different than their peers.[29] Parents with strong emotion regulation may be better equipped to soothe their children's anxieties and navigate family tensions spurred by this. As children transition to adolescence, they are expected to become increasingly independent in their T1D management, ongoing parent involvement in diabetes care throughout the adolescence, as the young person gains self-management skills and self-efficacy, is linked with higher adherence and lower HbA1c.[30, 31] For this reason, Lansing, et al.[16] hypothesized that when adolescents have parents with high SR, complex tasks feel easier to complete and adolescents are more likely to complete their treatment regimens. For example, in a situation that requires extensive planning, such as a sports tournament or on an overnight trip, parents with strong SR can assist adolescents in deciding how and when to manage blood glucose checks, review glucose patterns, and make decisions about adjusting insulin doses. Without this support, these tasks may exceed an adolescent's SR capacity.

Existing Evidence Regarding Parent SR and Youth T1D Management

Only a small number of studies have examined the role of parent SR in children's T1D management. Among these studies, Lansing, et al.[16] and Campbell, et al.[32] drew from the same cohort of youth with T1D to examine concurrent and prospective associations between mothers' and fathers' SR, youth-reported treatment regimen adherence, and youth HbA1c. SR was assessed with the 11-item Brief Self-Control measure[33], which measures an individual's perceived ability to control their thoughts, emotions, impulses, and performance. Lansing, et al.[16] studied the families when the youth were younger (mean age = 13.5 years) and found that mothers' and fathers' SR, as well as the interaction of mothers' and fathers' SR, were positively associated with the extent to which youth reported ease with performing their treatment regimen. That is, youth were the most likely to report their treatment regimen was easy to adhere to when both their mothers and fathers had high SR, particularly in comparison to families in which only mothers had higher SR or families where both parents had lower SR.

Using data from when the same youth were slightly older (mean age = 14.1 years), Campbell, et al.[32] similarly identified that higher maternal SR was associated with greater youth treatment regimen adherence concurrently, as well as 6 months later. Further, interactions between family conflict and mothers' SR were evident; higher family conflict was associated with poorer youth treatment regimen adherence only in families of mothers with lower SR. When considering fathers, no associations were observed between fathers' SR and youth treatment regimen adherence using data from this time point. It is not immediately evident why fathers' SR may matter more to youth treatment regimen adherence at one age, and then not again approximately 6 months later. These differences in findings between the two studies may reflect measurement error or limited statistical power

to detect small associations. However, similar to among mothers, fathers' SR moderated relationships between family conflict and youth T1D outcomes. Specifically, family conflict was only a risk factor for poor child treatment regimen adherence and high HbA1c in families of fathers with low SR. Study authors hypothesized that these moderated relationships may exist because most families experience conflict regarding adolescents gaining independence of their T1D. However, parents with lower SR may find managing this conflict particularly difficult, and may even escalate it, leading to disruptions of youth T1D management.

Among a smaller sample of families with a child between the ages of 3 and 18, Healey, et al. [34] examined associations between components of parent SR (effortful control, or the ability to focus attention and control impulses), and negative affect and surgency (which characterize emotion regulation capacity), and youth HbA1c. Among these families, stronger parent effortful control was associated with lower HbA1c levels among youth; however, no associations were found between parents' negative affect and surgency and youth HbA1c. The authors concluded that effortful control contributes to more effective planning and organization, which is essential to participating in treatment regimens.

Because of the different approaches to measuring SR used among the three studies in this area, as well as the different ages examined, comparison across studies is difficult. However, all three studies add support for the hypothesis that parent SR, and particularly mothers' SR, is important for youth treatment regimen adherence and glycemic control. Further, the findings of Healey, et al.[34] suggest that different components of parent SR may differentially support youth treatment regimen adherence and health outcomes.

Interactions between Parent and Youth SR

Beyond looking the effects of parent SR on youth T1D management and outcomes, understanding how parent and youth SR may work together (i.e., Path 3 of our conceptual model) is important for identifying families who may be at highest risk for poor treatment regimen adherence and need unique support. However, very few studies have considered how varying combinations of parent and youth SR interact among families of youth with T1D. In one study, Goethals, et al.[35] assessed parents' and youth's executive function in relation to youth treatment adherence and HbA1c among mother/youth dyads (child ages 6–18). Among this sample, contrary to studies that identified associations between mothers' SR broadly and youth treatment adherence, mothers' executive function was not associated with youth treatment adherence or HbA1c. However, the highest level of treatment adherence was evident when both mothers and youth had high executive function. The poorest glycemic control occurred among youth where both members of the dyad had low executive function. These results regarding the joint influence of mother and child executive function support our hypothesis (Path 3) that parents' SR modifies associations between youth SR, youth treatment regimen adherence, and youth glycemic control. Specifically, shared high or low SR among parents and youth may amplify the effect of youth SR on health behaviors. In contrast however, Healey, et al.[34] did not find evidence of interactions between parent and youth SR. This may be due to the limited sample size of this study and the wide age range of youth included. Use of a cohort with limited ability to stratify findings

by child age may mask differences in the importance of interactions between parent and youth SR as youth age.

Beyond the few studies that have assessed parent and child SR, other research has examined how specific parent characteristics support effective T1D treatment regimen adherence among youth with weaker SR. For example, among adolescents with T1D, Lansing, et al. [36] reported that lower youth future orientation (operationalized as delay discounting, or the extent to which individuals prefer immediate over delayed rewards) was associated with higher HbA1c levels. However, when parents reported that they frequently observed their child's diabetes care (e.g., monitoring youth's CGM), differences in HbA1c levels between youth with strong and weak future orientation were no longer significant. As consistent parental observation of youth T1D management likely requires strong SR, these findings provide further evidence suggesting that if parents can regulate their own behavior, they may be able to compensate for weak SR among youth.

In summary, research that considers parental SR capacity is limited, particularly in light of the growing recognition of the impact of youth SR in T1D management.[8, 9] Across the studies that do exist, different approaches to measuring SR limit our ability to compare findings. Further, the varying age ranges of children included in these studies may mask differences in the extent to which parent SR matters to youth T1D outcomes during different developmental periods. Despite these limitations, there appears to be a signal supporting our conceptual model, indicating that parent SR may be an important contributor to treatment regimen adherence and glycemic control among youth with T1D. Further, it may be that when multiple family members have stronger SR, whether it be both parents or parent and youth, these joint SR skills provide families resilience to better weather the challenges of T1D.[37]

Future Research Priorities

While small in number, existing studies suggest that a deeper understanding of how parent SR influences youth with T1D is warranted. Larger and more diverse cohorts of families of youth with T1D are needed to ensure generalizability of study findings and sufficient statistical power to reliably identify these relationships. Nearly all studies in this area have included 200 parent/child dyads or fewer, which is likely insufficient to identify consistent, meaningful interactions between parent and youth SR.[38] Relatively small sample sizes also limit the ability to understand the roles of parent and youth SR among different family structures (e.g., single parent families vs. families with multiple caregivers involved with T1D management). Finally, longitudinal studies of large cohorts including youth across different developmental periods (e.g. early childhood, school-age, adolescent), as well as rigorously-designed studies focused on specific developmental periods, are essential for understanding how the impacts of parent SR, and the interplay of parent and youth SR, change as youth develop. Programs such as the T1D Exchange Clinic Registry,[39] national registries in European countries, or clinical data research networks (e.g., <https://pcornet.org/>) provide opportunities to access larger, diverse populations of pediatric T1D patients and their families.

Socioeconomic diversity is an additional factor that is not reflected in current research on parent and youth SR and youth T1D management. Persistent socioeconomic disparities exist in youth T1D management and outcomes; low-income youth experience poorer glycemic control, greater risk of serious adverse events, such as diabetic ketoacidosis (DKA), and greater diabetes-related mortality than their higher income peers.[40, 41] While deprivation and discrimination are key underlying determinant of disparities in T1D,[42] low-income individuals and individuals who experienced poverty early in childhood are also more likely to experience SR deficits.[43, 44] Reduced SR capacity among low-income individuals, particularly when faced with needing to make high-impact decisions under emotionally stressful and resource-constrained conditions,[45, 46] likely exacerbates difficulties in T1D management. Epidemiologic research that includes diverse populations can provide important evidence regarding the extent to which differences in parent and youth SR serves to explain socioeconomic disparities in youth T1D management. If this is the case, SR-informed intervention strategies, described below, present a novel approach to improving the health of low-income youth with T1D.

Finally, this area of research would benefit from consistent inclusion of standardized measures of SR to allow for greater cross-study comparison of findings. Existing studies of parent SR in the context of youth T1D have all used self-report measures that assess problems in SR. Capturing SR via self-report, such as by using the Brief Self-Control measure,[33] the Behavior Rating Inventory of Executive Function for Adults (BRIEF-A), [47] which includes a measure of emotion regulation, or the Short Self-Regulation Questionnaire (SSRQ),[48] is useful because these measures are believed to capture “real world” SR and thus have relatively high ecological validity.[49] However, standardized behavioral tasks, such as the performance-based measures in the NIH Toolbox[50] have been recommended to complement self-report measures and identify deficiencies in individual components of SR.[49] Using these measures would aid in understanding how strengths and weaknesses of executive function, emotion regulation, and future orientation, both independently and jointly, influence diabetes-supportive family processes.

Implications for Youth T1D Management

Understanding the impacts of parent SR, alone or in combination with youth SR, on youth T1D is important for at least three reasons. First, if lower parent SR meaningfully inhibits youth T1D treatment regimen adherence and contributes to poor glycemic control, families who may struggle with T1D management can be identified earlier and provided greater support. Relatively low burden, self-report measures can identify adults with SR impairments. These measures would be simple for parents to complete in the clinic and offer providers insight into the family context in which youth and parents will be engaging in T1D management. Further, as 8% of adults in the US have received a diagnosis of ADHD,[51] identifying whether parents of youth with T1D have ever been diagnosed with ADHD could aid in developing and recommending more feasible treatment regimens. This could be accomplished by including simple questions regarding parent lifetime history of an ADHD diagnosis when assessing youth’s family medical history. Providing the context for these assessments—that understanding how parents plan, organize, and manage their emotions

will aid in the development of more personalized and effective family T1D management plans—is likely to increase parents receptivity to providing this information.

Second, there are unique learning approaches and compensatory strategies known to bypass the need for strong SR and support behavior change among individuals with lower SR.[52–54] For example, simplifying regimens, minimizing barriers to medications, and providing behavior prompts can reduce the complexity of T1D treatment regimen adherence.[55] Establishing simple routines in the home can also serve to minimize conflict, which may be exacerbated when parents have poor emotion regulation. Behavior scaffolding (e.g., using behavior checklists) and externally cueing behaviors (e.g., setting phone alarms or automated text message reminders) are two strategies that may be particularly useful to parents with low executive function.[56, 57] Additionally, automating tasks, such as signing up for automatic renewals of prescriptions or shipments of T1D supplies, or scheduling multiple diabetes clinic appointments at a time, can relieve a significant burden for parents who struggle with implementing plans and following through on tasks. It may also be beneficial to help parents with lower SR conduct “environmental scans” of their homes to identify existing structural supports that make it easier to engage in T1D treatment regimens. Examples of these structural supports include re-organizing the refrigerator so that healthier foods are more accessible or placing a child’s diabetes supplies near their backpack every night. These strategies may not only directly improve youth’s treatment regimen adherence, but also minimize family frustration, interpersonal conflict, and lapses in family communication, particularly in families where multiple members have lower SR.

Although several of these strategies are still being rigorously evaluated, evidence also suggests that specific SR processes can be strengthened among adults. Poor quality sleep, physical inactivity, and higher weight are all associated with lower SR.[58, 59] Focusing on parents’ self-care and ensuring that they have support for engaging in healthy behaviors and reducing stress themselves could increase their capacity to navigate T1D. Furthermore, specific intervention approaches, such as Episodic Future Thinking, are producing promising improvements in SR processes (e.g., future orientation) and health behaviors among adults with lower SR.[60–64] With Episodic Future Thinking, individuals are guided through an exercise to picture in detail future events and the decisions necessary for those events to occur. For example, parents may visualize an upcoming family vacation where they would like there to be minimal family conflict and their child’s T1D treatment regimen to be simple to implement. Those future events become “cues” that parents are reminded of each day to prompt engagement in the daily behaviors that will make the long-term goal happen. Recent pilot testing of Episodic Future Thinking indicates that the process can modify parenting behaviors.[65, 66] Translating this approach to the context of parenting youth with T1D, either as a standalone intervention or integrated into existing T1D management interventions, has great potential.

Conclusions

Preliminary evidence provides support for our hypothesis that parent SR impacts youth T1D management and outcomes via three related pathways: SR supports parent engagement in diabetes-supportive family processes including adaptive communication and direct parent

participation in youth T1D management; SR supports parents' ability to create family environments that encourage optimal SR development among youth, allowing youth themselves to better attend to their T1D management; and parents and children "load share", enhancing the impacts of one another's SR or making up for limitations of the others' SR. Emerging evidence suggests valid and meaningful approaches to identify and support parents with limited SR. Ultimately, these interventions may be able to assist families to more successfully manage T1D and improve the proportion of youth with T1D who achieve optimal glycemic control.

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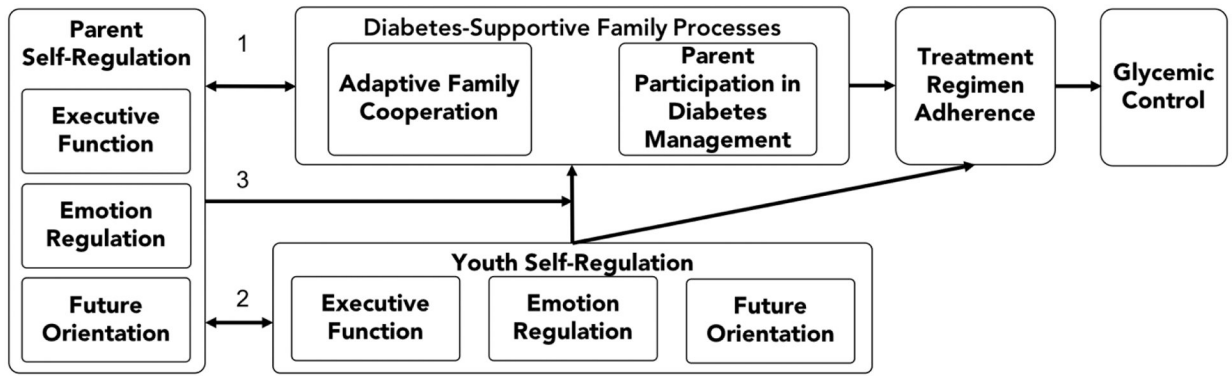


Figure 1.
 Conceptual Model of the Impacts of Parent Self-Regulation on Youth T1D Management and Outcomes.