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Abstract

The Pediatric Self-Management Model provides an overview of how behavioral factors influence children's chronic medical illnesses. This general framework is used to organize the present review of how self-management behaviors, contextual factors, and processes impact health outcomes for adolescent youth with type 1 diabetes. Adherence has been widely studied in the diabetes literature, and there are consistent findings demonstrating associations between aspects of self-management, adherence, and metabolic control, yet there are still equivocal approaches to adherence assessment methodology (e.g. global versus specific measures). Metabolic control is a hallmark health outcome for youth with type 1 diabetes, but additional outcomes need to be further explored. Future research should utilize the Pediatric Self-Management Model's operational definitions to guide empirically-supported interventions for youth with type 1 diabetes.

Keywords

Behavioral factors, type 1 diabetes, youth

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Adherence to medical regimen is often identified as a hallmark modifiable factor that impacts health outcomes for those with chronic medical illnesses. Rapoff suggests that adherence to medical regimens is estimated to be between 50–55 % for all chronically ill patients.¹ He describes a number of patient and family (e.g., demographic, adjustment/coping, family involvement), disease- and regimen-related correlates to adherence; however, correlates do not imply causation and should be interpreted cautiously.¹ Researchers have rated non-adherence rates to be between 20 to 93 %^{1–3} for youth with type 1 diabetes and have found that adherence is widely accepted as related to diabetes control.⁴

In a recent review article, Modi et al. make a distinction between two constructs: self-management (i.e., the interactions of health behaviors and related processes that patients and families engage in to care for chronic medical conditions) and adherence (i.e., the extent to which a person's behavior coincides with medical or health advice).⁵ In their Pediatric Self-Management Model, self-management influences adherence, which then affects outcomes, including health outcomes. The authors also suggest that there may be certain self-management factors that impact outcomes without the mediating role of adherence in pediatric conditions.⁵

This present review article will focus on the first two of three stages in the Pediatric Self-Management Model, self-management and adherence, to discuss the behavioral factors that may influence health outcomes for youth with type 1 diabetes during adolescence (see *Figure 1*). Findings from individual, family, peer, and group therapy interventions that have

targeted these behavioral factors in order to improve health outcomes will then be outlined.

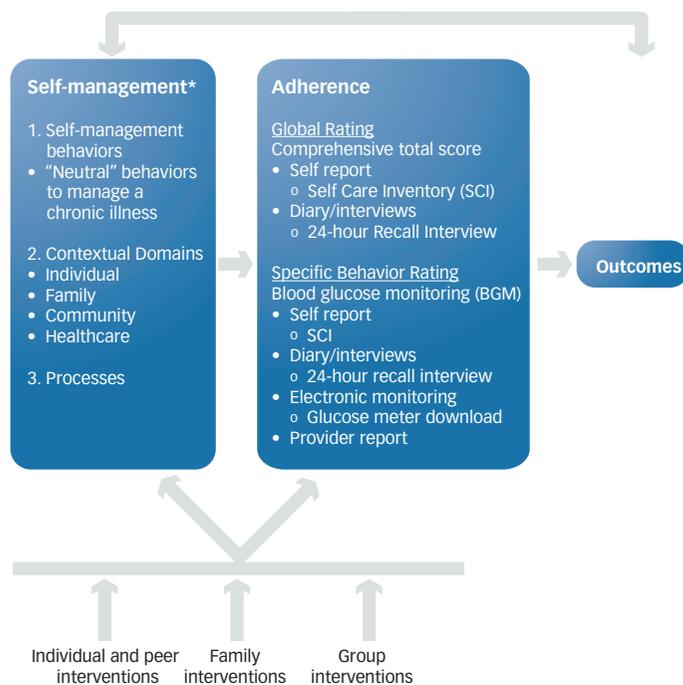
Self-management

Modi et al. describe the construct of self-management as having three components.⁵ The first component is self-management behaviors, which are the actual behaviors performed by the youth and/or family in order to care for a chronic medical illness. Secondly, there are contextual variables, which are four systems that impact how the self-management behaviors occur. These include individual, family, community, and healthcare domains. Finally, there are processes that link the self-management behaviors with the contextual systems. These processes include individuals' cognitive, emotional, and social perceptions. Three components of self-management, self-management behaviors, contextual variables, and processes as they relate to youth with type 1 diabetes, will be reviewed below (see *Table 1*).

Self-management Behaviors

Self-management behaviors, defined as examples of the 'neutral' behaviors that are employed to help manage a chronic medical illness, have been widely examined in youth with type 1 diabetes. Some examples of self-management behaviors that researchers have repeatedly identified as relevant to the management of diabetes are parental involvement and collaboration, the division of diabetes care responsibility in the family and subsequent transfer of diabetes care during adolescence, and parent-youth communication.

Figure 1: The Pediatric Self-Management Model Applied to Behavioral Factors Associated with Health Outcomes in Youth with Type 1 Diabetes



*For specific examples see Table 1.

Regarding parental involvement and collaboration, some researchers have found that increased parental involvement is associated with more conflict among parents and youth, which then may decrease the youths' willingness to adhere to their diabetes regimen.⁶ However, the general consensus in the literature appears to be that parent involvement and collaboration between parent and youth in diabetes tasks have been found to be compensatory and significantly predict improved adherence to the diabetes regimen in general, especially if this collaborative involvement comes from the primary diabetes caregiver.⁷⁻¹⁰ Higher levels of parental readiness to change the balance of responsibility of diabetes care from parent to youth has also been shown to be related to more youth diabetes responsibility and self-efficacy (i.e., the perceived ability to manage diabetes care) as well as decreased general parental stress.¹¹ Some researchers have suggested that too much independent responsibility for diabetes tasks in youth with type 1 diabetes may compromise diabetes self-care, even if it promotes maturity.¹² Therefore, the transfer of this care needs to be conducted in a way that supports the youth's autonomy, without decreasing one's adherence.^{13,14} There is also evidence that increased positive family communication as well as high levels of diabetes knowledge are helpful in minimizing parent-youth verbal conflict regarding diabetes care.¹⁵

Contextual Variables

Four types of contextual variables are systems (i.e., individual, family, community, and healthcare system) that influence the youth and impact their self-management. These variables can be either modifiable or non-modifiable and are outlined below.

Individual

Individual characteristics that have been widely examined include youth demographics, cognitive abilities, psychological functioning, personality/coping style characteristics, and disease-specific characteristics. Considering youth demographics, research consistently shows that age is associated with adherence, where older youth are often found to have poorer adherence to their diabetes regimen.^{16,17} More research is emerging, which demonstrates that one's cognitive abilities, as measured by executive functioning (i.e., the ability to regulate behavior, metacognition, and cognitive autonomy) also play a role in successful diabetes self-care, beyond the influence of youth age.^{16,18} Diabetes numeracy, the numerical skills needed to complete diabetes self-management tasks, has also been found to be related to improved diabetes knowledge, self-efficacy, and glycemic control in adults,¹⁹ yet this body of research needs to be extended to youth with type 1 diabetes.

Concerning psychological functioning, both internalizing (e.g., social anxiety and depression) and externalizing (e.g., acting out behaviors) problems are significant contributors to adherence across genders.²⁰⁻²² In particular, there is evidence that symptoms of depression and anxiety may disrupt adherence through decreased concentration, impact on judgment ability, memory impairment, and decreased motivation and energy, which are all symptoms of the disorders themselves.²³⁻²⁵ Additional psychological characteristics that have been found to be related to diabetes adherence and subsequent glycemic control are maladaptive eating attitudes and behaviors, including the potential for insulin omission for the purposes of weight control.²⁶

The relationships among certain personality characteristics (e.g., conscientiousness, extroversion, neuroticism, impulsivity, and assertiveness), individual coping styles (e.g., stress management), and diabetes management have also been examined.^{27,28} Specifically, high youth conscientiousness and extraversion are associated with higher rates of completing diabetes cares, while high neuroticism and low conscientiousness are predictive of decreased adherence and a need for increased monitoring by parents throughout adolescence.²⁸ Researchers found that youth's general stress impacts their adherence, especially for completing blood glucose monitoring (BGM), as the endorsement of high levels of general stress is indicative that youth may be experiencing stress regarding health, finances, living situations, parents, siblings, school, and friends.²⁷

There are also disease-specific factors, including length of time since type 1 diabetes diagnosis, that also seem to impact adherence to diabetes self-management tasks, but these findings are more equivocal. Some researchers suggest that youth with a longer duration of diagnosis feel more comfortable with BGM and are more at ease with doing their diabetes care in public,²⁹ while other studies have found that longer duration of diabetes is related to lower self-reported adherence rates^{27,30} and diabetes 'burnout'.³¹ Researchers have looked at the interrelationships of multiple variables that may also impact the association between length of time since diagnosis and adherence. They found that when these covariates are examined, age moderates any gender differences that were previously found in adherence, and the effects of duration of diabetes on adherence also appear to be mediated by youths' depressive symptoms.²¹ Therefore, diabetes duration may have both a positive and negative impact

Table 1: Examples of Self-management Factors in Youth with Type 1 Diabetes

Self-management Behaviors	Contextual Variables (Modifiable and Non-modifiable)	Processes
Parental involvement/collaboration Division of diabetes responsibility Transfer of diabetes care Parent-youth communication	Individual: Age Executive functioning Youth anxiety/depression Externalizing behaviors Stress	Cognitive: Health beliefs Compensatory beliefs
	Family: Household organization/chaos Spousal/partner support Distribution of parental roles Maternal anxiety/depression	Emotional: Threat to well-being Self-efficacy
	Community: Teacher victimization Peer pressure/bullying	Social: Decision making skills Social attributions
	Healthcare: Provider-patient relationship	

on diabetes care, and other factors may be even more relevant to overall adherence in youth with type 1 diabetes.

Family

The research with youth with type 1 diabetes related to the second contextual variable, the family system, has focused on examining multiple characteristics, such as socio-economic status (SES), ethnicity, family structure and organization, spousal/partner support, distribution of parental responsibilities, and parental psychological functioning. Specifically, families with heightened financial strain had poorer treatment outcomes and adherence.^{32,33} In a study of Hispanic youth with type 1 diabetes, those who had more recent generational status (i.e., their parents had immigrated more recently) in the US had better adherence. The authors hypothesize that those who are less acculturated may have greater respect for medical staff, which may be associated with better adherence.¹³ Researchers examined the relationship between adherence and a number of family structure variables, including maternal employment status, while controlling for the influence of youth age, pubertal status, SES, duration of diabetes diagnosis, gender, and ethnicity. They found no differences in self-care adherence for the family structure variables.³⁴ The researchers did find that older age of youth and more advanced youth pubertal status were two variables associated with better adherence; therefore, they cautioned diabetes providers from stereotyping families based on their presenting family structure only (i.e., assuming that families from households where the mother is employed have worse adherence).¹⁶ Other researchers examined family organization and household chaos characteristics and found that high amounts of child routines in the household positively impact diabetes self-care.¹⁷

Both the amount of spousal/partner support felt by maternal caregivers and the division of parental responsibilities in caring for youth with type 1 diabetes have been found to be important. The literature suggests that maternal perceptions of support from her spouse/partner and involvement of paternal caregivers is beneficial to both maternal and youth functioning.³⁵ Higher levels of paternal support is hypothesized to minimize maternal sense of helplessness and decrease diabetes-related

verbal conflict between maternal caregivers and youth.^{36,37} Researchers have also identified that both maternal and paternal caregivers may have different, but equally important, roles in supporting youth's diabetes management.^{37,38} Specifically, maternal and paternal caregivers who have more positive relationships with their child and demonstrate regular monitoring also have youth with better adherence.³⁸ Behavioral involvement in daily diabetes care tasks by maternal caregivers was associated with better adherence, whereas father behavioral involvement in daily diabetes care tasks was related to poorer adherence among youth with type 1 diabetes.³⁸ Therefore, parenting behavior and gender are important to take into account when examining maternal and paternal roles in promoting diabetes adherence in youth with type 1 diabetes.³⁷

One additional family factor that has been found to significantly impact adherence among youth with type 1 diabetes is maternal psychological functioning, including separation anxiety and depression.^{16,39} Maternal caregivers, who demonstrate difficulties with separation anxiety and attachment issues with their adolescents, are hypothesized to also have difficulties with their adolescent's eventual need for autonomy for diabetes care.¹⁶ Similarly, higher maternal depressive symptoms have been found to be associated with poorer youth diabetes adherence.³⁹ Researchers suggested that the maternal depression symptoms may impede the ability of mothers to facilitate their youth's self-management skills over time.³⁹

Community

Less research has been conducted regarding the third contextual variable, community, yet multiple studies have focused on the role of teachers and peers in impacting adherence among youth with type 1 diabetes. One study examined how negative (i.e., victimizing) teacher-youth interactions played a role in youth's diabetes adherence. They found that these challenging interactions decrease diabetes self-management behaviors for younger children, but not adolescents ages 12 and older.⁴⁰ Negative peer influences have been shown to be detrimental to diabetes adherence among youth with type 1 diabetes, yet a strong parental foundation is thought to protect against this negative peer pressure.⁴¹ Youth who have

reported being bullied or teased about type 1 diabetes have poorer adherence, especially for the more public and observable diabetes tasks (e.g., BGM and insulin administration).⁴² However, other researchers have attempted to determine whether certain peer groups can promote positive peer influences and have found that training in diabetes support among peers is helpful to building social support for youth with type 1 diabetes.^{43,44} Diabetes camps are also a community resource for youth with type 1 diabetes and future research is warranted to determine if diabetes camps serve as a potential protective factor for adherence.

Healthcare System

The final contextual variable proposed in the Modi et al. model considers the role of the healthcare system.⁵ Research in this area often focuses on examining the patient-provider relationship and communication. More patient-centered communication by the physician has been found to be related to better adherence and metabolic control.⁴⁵ Youth's perception of support from their diabetes physicians and nurses has been found to be influential in helping patients share their concerns and be honest with medical providers about their diabetes, which ultimately helps improve diabetes adherence.³⁰ It is important for healthcare systems (i.e., diabetes clinics) to determine effective ways of assessing self-management behaviors as well as the contextual factors (e.g., individual and family systems) in routine clinical visits. For example, the assessment of psychological characteristics, such as depressive symptoms, among youth with type 1 diabetes should be integrated into the diabetes clinic visits using well-validated measures.²⁵

Processes

The third component to Modi et al.'s self-management model examines the processes that influence how the self-management behaviors and contextual variables interact.⁵ Researchers have attempted to understand how different individual perceptions of the world (e.g., cognitive, emotional, and social processes) link self-management and contextual variables.

The Health Belief Model (HBM) describes the potential influence of cognitive processes, such as one's perceptions of how certain behaviors do or do not have the potential to impact health outcomes.⁴⁶ The HBM findings are mixed.^{9,29,47} Some researchers describe the importance of this model in understanding youth's health locus of control and how it may produce better health outcomes.⁴⁷ Others do not find the HBM to be adequate as it does not take into account other potentially influential psychosocial factors,⁹ and it has not been predictive of diabetes adherence.²⁹ The use of compensatory beliefs, or rationalizing that the negative effects of one behavior (e.g., not doing BGM) can be counteracted by other compensatory behaviors (e.g., skipping breakfast), have also been examined. These maladaptive convictions are hypothesized to alleviate any mental conflict over engaging in behaviors that are at odds with one's diabetes regimen recommendations, and they have been shown to be predictive of poorer BGM adherence in youth with type 1 diabetes.⁴⁸

Research has also explored how emotional processes may influence adherence among youth with type 1 diabetes. Specifically, researchers found youth's views about diabetes and its treatment as a threat to emotional well-being. Youth perceptions of threats to emotional well-being was the best predictor of adherence when compared to

other variables, such as physician and nurse support, motivation to comply, energy to complete the tasks, and views of diabetes as a threat to physical well-being.³⁰ Youth who perceived diabetes as a threat to emotional well-being were 7.68 times more likely to complete their diabetes care tasks, than those who did not hold those views.³⁰ Researchers are not endorsing the use of 'scare tactics' to increase the perception of diabetes as a threat to youth with type 1 diabetes, but rather they suggest that efforts should be made to instill a sense of higher self-efficacy in being able to manage their health through increased maternal empathy and perceived support from diabetes physicians and nurses. It is anticipated that these beliefs will then promote motivation, energy, and willpower to improve health outcomes for youth with type 1 diabetes.^{30,49}

Two social processes that have been examined among youth with type 1 diabetes include youth's acquisition of decision-making skills from their family of origin⁵⁰ and the impact of negative social attributions of peers.⁵¹ Specifically, researchers found that negative family communication resulted in youth with type 1 diabetes observing the family decision making process as pessimistic. Youth who experienced negative family communication also lacked the ability to take responsibility for their own behaviors, and they were less able to take others' perspectives. It is likely that all of these characteristics impacted how diabetes responsibility and management were allocated and executed in the family.⁵⁰ The social information processing model outlines how youth with type 1 diabetes, who engage in higher amounts of negative attributions, misinterpret that peers will react negatively if they observed youth completing diabetes tasks. More negative assumptions have been found to be associated with poorer adherence, especially when adolescents are in social situations.⁵¹

Adherence

Adherence is often defined as, "The extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice".⁵² Despite the relative consensus on a definition of adherence, there are often different approaches to operationally assessing and measuring adherence.⁵³ Some researchers focus on global, comprehensive assessments of adherence, while other focus on specific adherence tasks separately. Therefore, the how, when, where, and by whom these adherence behaviors are assessed, result in different ratings of degrees of medical adherence.⁵³ It is recommended that adherence measures should be continuous, dynamic, and capture specific regimen behaviors relevant to the disease population.⁵⁴

Diabetes-specific Adherence

Similar to youth with other chronic medical illnesses, youth with type 1 diabetes have been shown to have difficulties with adherence to their medical regimen. Assessment of diabetes regimen adherence has included both measures that have been used to provide global information about adherence (e.g., summary scores from self report measures) as well as measures that provide information about specific adherence behaviors (e.g., BGM). Thus, both the multidimensional nature of the diabetes regimen as well as the type of adherence assessment method used is important for researchers and clinicians to consider. Recent work by Quittner et al.¹ and Rapoff⁵⁵ examined adherence assessments that were related to the individual's execution of the recommended medical

regimen for pediatric patients with a wide variety of chronic diseases, including type 1 diabetes. Quittner et al. reviewed three different accepted methods of assessing diabetes adherence behaviors in youth: self-report measures [e.g., Self Care Inventory (SCI)], diary/interview measures (e.g., 24-hour Recall Interview), and electronic monitoring (e.g., blood glucose meter download).⁵⁵ In general, Quittner et al. recommended that one additional assessment measure be utilized along with an electronic monitoring measure for all adherence research. A more thorough review of the strengths and weaknesses of each method of assessing diabetes adherence is beyond the scope of this review and is summarized fully in Quittner et al.⁵⁵

Although diabetes regimen adherence has been measured using different methods (e.g., self-report measures, diary/interview measures, and electronic monitoring), there is empirical evidence demonstrating the associations between many of these adherence measures and glycemic control.^{26,56} There are also well-established relationships between global measures of adherence (e.g., SCI)⁵⁵ as well as specific diabetes adherence behaviors (e.g., BGM) and glycemic control. BGM is the one specific diabetes regimen adherence behavior that has been repeatedly found to be a primary determinant of glycemic control.⁵⁷⁻⁶⁰ The assessment methodologies utilized for assessing BGM in these studies are varied (e.g., self-report, diary/interview, meter downloads, and/or provider ratings), and they are all still fraught with concerns about reliability and validity.^{55,61} Despite this lack of consensus on how to best assess BGM, BGM is still often utilized as an indicator of a patient's overall adherence to one's diabetes-specific medical regimen.⁵⁶

Diabetes-specific Interventions

As researchers have continued to identify the self-management characteristics that impact adherence, a variety of psychological interventions have sought to address modifiable characteristics. The next section will review the efforts of individual and peer, family, group, and the combination of family and group interventions in addressing self-management, adherence, and outcomes for youth with type 1 diabetes.

Individual and Peer Interventions

As outlined by Wysocki et al., there have been many individual and family interventions that focus on behavioral management, communication and problem-solving, as well as stress, coping, and psychological adjustment.⁴ In addition, there have been a number of interventions that have targeted peers and social interactions for youth with type 1 diabetes.^{44,62} Researchers found that participant support from a best friend impacted youths' adjustment to type 1 diabetes by increasing their diabetes knowledge and social support for their diabetes care.⁴⁴ Similarly, preliminary analyses examining an intervention which targeted retraining negative social attributions in youth with type 1 diabetes demonstrated that problem-solving strategies were helpful in improving youths' reported adherence in social situations.⁶²

Family Interventions

Family-based interventions, such as multisystemic therapy (MST)⁶³ and behavioral family systems therapy (BFST),⁶⁴ have been used to help improve diabetes management in youth. MST family-based interventions are conducted in youths' homes with their family members and have

been found to positively impact both adherence to frequency of BGM recommendations as well as health (i.e., metabolic control) and individual (i.e., inpatient admissions) outcomes, especially among those who chronically evidence poor diabetes control. Researchers found that family-based interventions using BFST showed improvement in self-management behaviors (i.e., parent-adolescent relationship and diabetes-specific conflict) as well as a health outcome (i.e., glycosylated hemoglobin [HbA_{1c}]) as compared with a randomized education group or a current therapy group.^{64,65} However, results of treatment, in terms of improving psychological functioning, varied by contextual variables (e.g., age and gender), which indicate a need for more research on the effectiveness of family-based interventions with males and females of various ages.^{64,65} Moreover, those participating in this family treatment did not report changes in adherence behaviors to their medical regimens. Therefore, it is also important to see if certain self-management interventions can impact outcomes without being mediated by adherence, similar to what Modi et al. suggest in their proposed model.

Group Interventions

Group interventions for youth with type 1 diabetes, which focus on providing peer support and developing problem-solving skills, have been able to improve outcomes, such as HbA_{1c} levels^{66,67} and quality of life (QOL) for those with insulin pumps.^{68,69} Stress management and coping skills training have impacted other outcomes, such as reduced diabetes-related stress⁷⁰ and improved social interactions.⁷¹

Combined Group and Family Interventions

Peer and family-based group therapies have been typically used as separate interventions with youth with type 1 diabetes. Opari-Arrigan et al. developed an intervention, which combines both family and peer group intervention strategies, by offering separate, but parallel, youth and parent groups.⁷² This group therapy intervention demonstrated improved readiness to change the balance of responsibility of diabetes care as reported by parents as well as an increase in parental involvement in the division of diabetes responsibility as reported by both the parents and youths.⁷²

In summary, many of these psychological interventions focused on behavioral factors that can be categorized as either self-management or adherence behaviors. These interventions targeted not only improved health outcomes, such as HbA_{1c}, but a variety of other outcome variables. Future research will need to continue to determine which outcome variables are important to target, in addition to the more traditional health outcome of HbA_{1c}, which is often resistant to clinically significant change in behavioral health interventions.

Future Implications and Recommendations

It has been well established that HbA_{1c} is one of the primary factors impacting long-term complications for individuals with diabetes⁷³ and is often considered the hallmark health outcome variable in research involving youth with type 1 diabetes. In addition to traditional health outcomes in chronic medical illnesses, the Modi et al. model outlines other individual (e.g., quality of life, school absences, and healthcare utilization) and system (e.g., treatment efficacy, clinical decision making, and healthcare delivery) outcomes that are also important to understand.⁵ Researchers have explored several of these other individual and system

outcomes, which are also influenced by self-management and adherence factors in youth with type 1 diabetes, but more research on these outcomes is warranted. An additional outcome measure that should be more fully explored is cost savings associated with an intervention.⁷⁴ Little attention has been paid to intervention cost-effectiveness and very few investigations have systematically examined how to translate research-based interventions into clinical settings, especially longitudinally.⁷⁵

The Modi et al. model⁵ is an empirically-derived model for pediatric chronic medical illness, in general, and includes an examination of self-management, adherence, and outcomes. This model has utility for organizing the large amount of behavioral health research on youth with type 1 diabetes; however, some questions remain to be examined empirically. For example, given the nature of the diabetes-specific medical regimen and its link to glycemic control, how does adherence act as

a mediating variable between self-management and health outcomes? Similarly, are there some self-management factors that can impact outcomes without adherence as a mediating variable? Researchers examining behavioral factors in youth with type 1 diabetes would benefit from framing future descriptions of their studies within the context of the Modi et al. model, which distinguishes between interventions that focus on self-management versus adherence (or both) to help understand how they impact health outcomes.⁵ As more children of younger ages are diagnosed with type 1 diabetes, researchers will need to expand the body of literature to understand the self-management, adherence, and outcomes for young children with type 1 diabetes. Modi et al.'s model can help drive the development and evaluation of empirically-supported interventions to modify diabetes-related behavioral factors at different developmental stages to improve diabetes outcomes, ultimately preventing complications and mortality in youth with type 1 diabetes. ■

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