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Title Page

Type 1 Diabetes in Very Young Children:

A Model of Parent and Child Influences on Management and Outcomes

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Abstract

The incidence of type 1 diabetes (T1D) in very young children (YC-T1D) is increasing globally. Managing YC-T1D is challenging from both a medical and psychosocial perspective during this vulnerable developmental period when complete dependence upon parental caretaking is normative and child behavior is unpredictable. The consequences of suboptimal glycemic control during this age range are substantial since these children will have T1D for many years and they are prone to adverse neuropsychological sequelae. Poor adaptation to T1D during these early years may engender a persistent trajectory of negative outcomes that can be very resistant to change. The empirical research on the YC-T1D population (age < 6 years) has indicated multiple mechanisms through which parent characteristics, parent coping skills and child characteristics interact to yield a pattern of T1D management behaviors that affect T1D outcomes. However, this research has not yet led to a well conceived conceptual model for identifying and understanding these mechanisms or for specifying research gaps and future research directions. The aim of this review is to propose such a conceptual model linking parent characteristics, parent coping, and child characteristics to T1D management behaviors and outcomes. This paper

reviews the literature focusing on research pertinent to YC-T1D and elements of our proposed model, identifies and discusses gaps in the literature, offers directions for future research, and considers a range of possible interventions targeting the unique needs of this special population.

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Abbreviations

BG: Blood glucose

HbA_{1C}: Hemoglobin A_{1C}

T1D: Type 1 diabetes

YC-T1D: Young child with type 1 diabetes

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Management and Outcomes

The prevalence of type 1 diabetes (T1D) in very young (age < 6 years) children (YC-T1D) was approximately 3.6% of cases in 2009 (1), but the incidence of YC-T1D may be increasing by up to 5.4% annually (2, 3). The public health impact of this trend is concerning, since these patients will have T1D longer, enduring more exposure to risks of long term complications (4, 5). Managing T1D in young children is challenging from medical and psychosocial perspectives (4). YC-T1D have high insulin sensitivity, nocturnal hypoglycemia is common, and both hypo- and hyper-glycemic exposure have been implicated in the etiology of cognitive sequelae (6). Young children have unique developmental challenges including normative dependence upon parental caretaking (7) and labile self-regulation of behavior and emotions (8), eating (9), sleep (10), and physical activity (11) that may complicate T1D care. While impressive technical advances have been made (12, 13), controlled trials of these technologies in YC-T1D have yielded equivocal results (13, 14) and the use of these technologies may increase the burden of YC-T1D care rather than reduce it (15, 16).

A thorough review of YC-T1D literature was recently published (17), although the research has not yielded an empirically supported conceptual model for identifying and understanding the mechanisms through which parent characteristics, parent coping, and child characteristics influence management and outcomes in YC-T1D. In this paper, we put forth a

conceptual model that attempts to account for the complexities of T1D care in this population and that reflects the multiple mechanisms that may affect YC-T1D self-management and outcomes (e.g., glycemic control, quality of life). Our model incorporates components of Wallander and Varni's disability-stress-coping model (18), that conceptualizes the youth's chronic illness as an ongoing family stressor and proposes risk and resiliency factors that influence the child's psychosocial adaptation. Components of Bandura's social-cognitive theory (19) were also incorporated into the conceptualization of our model including the emphasis of self-efficacy and outcome expectations as important determinants of behavior. Parental self-efficacy, particularly mastery over skills related to managing YC-T1D, may impact their ability to cope with the unique demands that they experience on a daily basis. These parents also have a responsibility to promote age-appropriate T1D self-management behaviors in their YC-T1D through which children can develop positive outcome expectancies. We have not found other explanatory models of the influence of parent and child factors on disease management behaviors and their influences on both medical and psychosocial outcomes. A model representing such relations would provide a frame of reference of the multiple influences on the management and outcomes of YC-T1D, as well as tool for identification of multiple targets of intervention with this unique population.

Below, we articulate the model, review studies that explore model elements, identify gaps in that research, offer directions for future research and consider interventions targeting the YC-T1D population. As seen in Figure 1, the model specifies individual characteristics of parents (e.g., sociodemographic characteristics, social support, parenting style, and prior psychiatric

history) that may influence parental coping with the affective, behavioral and cognitive challenges associated with managing YC-T1D. The model asserts that parental coping with these challenges will have direct effects on T1D management behaviors and indirect effects mediated by individual child characteristics (e.g., age, temperament, impulsivity, executive function). The model contends that the parent and child characteristics interact to yield a pattern of T1D management behaviors that affect T1D outcomes (e.g., HbA_{1C}, hypoglycemia and quality of life).

Individual Parent Characteristics

Unlike T1D management in older youth, effective management of YC-T1D relies solely on parents or other caregivers (20). We propose that individual parent characteristics influence how parents cope with the challenges of managing YC-T1D. Some of these characteristics are modifiable and amenable to intervention (e.g., social support, parenting style, parental coping, child behavior problems), whereas others are much less amenable to intervention (e.g., sociodemographic characteristics). A number of studies, which are discussed below, provide evidence suggesting that the incorporation of individual parent characteristics (i.e., sociodemographic factors, social support, parenting, and pre-morbid psychiatric issues) is relevant to the model.

Sociodemographic factors. Most studies examining associations of parental sociodemographic characteristics (i.e., race, ethnicity, marital status, socioeconomic status) with T1D outcomes focus on older youth, but a few have studied YC-T1D. In one study, YC-T1D with married, compared with single, parents were likely to have more blood glucose (BG) levels

in the target range and better glycemic control (21). A study that screened parents of youth at T1D diagnosis, including YC-T1D, showed that receiving public aid, single parent marital status, and caregiver education less than high school predicted future diabetes-related emergency department admissions (22). Controlling for racial differences, poorer glycemic control was better accounted for by lower socioeconomic status and single parent marital status in older youth with T1D (23). In addition to influencing T1D outcomes, demographic variables appear to affect parent functioning as well. The only YC-T1D study of this type showed that single mothers and mothers of non-white youth with T1D, including YC-T1D, endorsed significantly diminished physical and psychological well-being (24). Taken together, it appears that parent marital status, education level, socioeconomic status, and racial/ethnic minority status are related to parental coping, T1D management behaviors, and T1D outcomes. Although these studies were cross sectional and causation cannot be implied, certain sociodemographic features may be considered risk or protective factors for impacting parental coping and T1D management and outcomes, which is reflected in our model.

Social support. Social support influences coping with T1D in parents of older youth (25-27), although empirical research examining this construct in parents of YC-T1D is sparse. Qualitative research indicates that, soon after diagnosis, parents have reported feeling isolated (28, 29). Mothers may be especially prone to these feelings when children are under four years old (28, 29). In another qualitative study, parents of YC-T1D also described isolation in caring for their YC-T1D and noted that family and friends had minimal understanding of T1D management (30). Additional research examining the influence of social support on T1D

management and outcomes (e.g., glycemic control, frequency of hypoglycemic events) is needed. However, given existing research that suggests parents of YC-T1D experience feelings of isolation and lack of understanding by families and friend, minimal social support is considered a risk factor in our model and may be a constructive point of intervention (62, 63).

Parenting styles. Several studies have examined relations between parenting styles and T1D outcomes. A review of research linking parenting styles to glycemic control and adherence concluded that higher family cohesion, parental warmth, and an “authoritative” style of parenting are related to better T1D health outcomes, whereas higher general family conflict, parental restrictiveness, criticism and an “authoritarian” style of parenting predicted worse outcomes (20). Examination of parent behaviors in 35 families of children (ages 2-8 years) with T1D revealed significant positive correlations between parents’ use of ineffective/coercive parenting strategies (e.g., coaxing and interrupted commands) and children’s dietary deviations and glycemic control (31). Given the link between parenting style and T1D outcomes, this construct is considered a risk/protective factor and a potential point of intervention in our model.

Pre-existing parental psychiatric history. Obtaining a detailed parental psychiatric history at T1D diagnosis might be valuable, but no YC-T1D studies have done so, nor has this been done in T1D epidemiology studies such as TrialNet (32). However, there are clear influences of parent psychological functioning (e.g., parental depression, anxiety, personality disorders, and attention-deficit/hyperactivity disorder) on child behavior (33). No behavioral science research on YC-T1D studied children before the T1D diagnosis, so it is impossible to disentangle the effects of T1D adjustment and coping in parents from pre-existing mental health

issues. However, given the links between parent and child psychological functioning and between parent distress and T1D outcomes (see below), pre-existing parent mental health issues are considered a possible risk factor in our model, although more study on these relations is warranted. Several authors have provided clinical recommendations and screening protocols which can assist with the identification of pre-existing parent mental health issues and facilitate opportunities for intervention (22, 34).

Parental Coping with T1D Challenges

Care of YC-T1D poses affective, behavioral, and cognitive demands for parents, and their responses may predict later T1D outcomes (22). These challenges include needle pain/phobia, BG monitoring, regulation of food intake, balancing insulin with carbohydrate intake, physical activity and prevailing glycemia, remediation of hypoglycemia and hyperglycemia, sick day management, getting sufficient sleep and managing T1D care away from home. Most studies examining parental coping with the challenges of managing T1D have focused on school-age and older children and mothers (35, 36). However, in one study of mothers of YC-T1D, those who found it more upsetting to cope with diabetes-related distress had significantly higher symptoms of anxiety and depression (37). We found only a single study examining parental coping in relation to T1D outcomes, which resulted in a nonsignificant relation between parental coping with the demands of YC-T1D and glycemic control (38). While more research is needed to examine the relationship between parental coping with the demands of managing YC-T1D and T1D management behaviors and outcomes, preliminary findings suggest that parental coping may represent an important target for intervention to improve

parental and child adjustment to T1D. Given that parents of YC-T1D must take on the burden of all T1D challenges and also negotiate the many developmental challenges that all young children encounter, our model suggests that parental coping with these challenges will have direct effects on T1D management behaviors and outcomes.

Parents' psychological functioning and adjustment post-diagnosis. Several studies have evaluated psychological distress in parents of youth with T1D, employing diverse measures of parenting stress, distress, and mental health symptoms (34). Pediatric parenting stress is a construct used to define stress specifically associated with raising a child with a chronic illness (39) and has been examined in several studies of parents of YC-T1D (35, 38, 40-42), often in conjunction with mental health symptoms including depression, anxiety, and post-traumatic stress. A systematic review of 34 articles on parental psychological distress in T1D indicated that 19% of parents reported clinically significant levels of distress, regardless of how it was defined, 1-4 years after diagnosis (34). The impact on parental psychosocial functioning was greater among parents of younger children with diabetes (28, 38). Studies indicate that YC-T1D parents' psychological distress is associated with lower income level (35), child behavior problems (40, 41), fear of hypoglycemia (42), nighttime BG monitoring (7), and lower parental monitoring of diabetes management (43). Studies examining relations between parent psychological distress and T1D outcomes yielded mixed findings. In two studies of parents of YC-T1D, no association between parental anxiety or parenting stress and glycemic control was found (35, 40), while another study of parents of YC-T1D indicated that increased parenting stress was associated with better glycemic control (38). While it is unclear whether there is a

direct relation between parental distress and children's glycemic control, perhaps some parents enlist effective ways of coping with their distress, while for others this distress impedes optimal care for YC-T1D. Thus, parental coping and psychological distress may indirectly affect T1D outcomes.

Fear of hypoglycemia. YC-T1D are susceptible to glycemic variability due to increased insulin sensitivity and unpredictable diet/physical activity. Further, their cognitive and verbal immaturity limits the accuracy of their symptom reporting which may present a challenge to recognizing and treating hypoglycemia. Parents often express significant fear of hypoglycemia that impacts T1D management and parental quality of life. One study examined fear of hypoglycemia in 24 parents of YC-T1D. Many parents reported significant worry about their YC-T1D having hypoglycemia during sleep (63%) or while away from a parent (46%). In the same study, 38% percent of parents reported worry about their child having a seizure and that no one would be able to help their child during hypoglycemia (44). Further, fear of hypoglycemia was associated with higher mean daily blood glucose levels (43). Understandably, a history of a hypoglycemic seizure strongly predicts fear of hypoglycemia (45-47). Fear of hypoglycemia falls on a continuum in that some level of fear is adaptive (i.e., may prevent hypoglycemic episodes), whereas higher levels of fear may lead to other poor parental coping skills (i.e., sleep disruption, anxiety) and maladaptive T1D management behaviors (e.g., purposefully administering lower doses of insulin). This is consistent with our model which indicates that parental fear of hypoglycemia may serve as a risk or protective factor for T1D management and outcomes (48).

Sleep disruption. Performing nighttime BG monitoring and T1D management may impede sleep quantity and quality of parents of YC-T1D (49). In a study of 71 parents of YC-T1D, parents who reported more frequent nocturnal BG checks also endorsed higher state anxiety and increased parenting stress (7). In another study, the same group found that 79% of parents indicated that nocturnal BG checks disrupted their own sleep, although glycemic control was unrelated to either the number of nocturnal BG checks or sleep disruption (50). A larger study of 134 parents of YC-T1D indicated that parents report less sleep time than recommended and greater sleep problems compared to standardized norms of healthy adults and that poorer sleep quality was associated with worse glycemic control and greater fear of hypoglycemia (49). It is unclear whether there is a direct relation between parental sleep quality and glycemic control. It is possible that parental sleep disruption may enhance glycemic control through timely interruption of glycemic excursions or impede glycemic control through diminished attention to the demands of the T1D regimen during waking hours. Thus, while it is unclear whether there is a direct relation between sleep quality and glycemic control, disrupted sleep may be considered a risk or protective factor for T1D outcomes which is supported in our model.

Individual Child Characteristics

Effective management of YC-T1D requires the parent to engender the child's tolerance of, and cooperation with, the demands of the T1D regimen. We propose that parent characteristics and coping skills have both direct and indirect effects (mediated by child characteristics) on T1D management behaviors and their glycemic and psychological outcomes. The indirect effects arise since parental coping with the affective, behavioral and cognitive

challenges posed by managing T1D are presumably mediated by the child's acceptance of, and cooperation with, the multiple demands comprising T1D care. The effectiveness of parental coping with these challenges is at least in part a function of child characteristics. The direct effects of child characteristics on T1D management may reflect the influences of the child's temperament, attention span, impulsivity, executive functioning, behavioral adjustment, food preferences, acceptance of novel foods, appetite, amount and variability of physical activity, and tolerance of painful or aversive procedures such as injections and finger sticks. Several studies affirm associations proposed in the model. Below, we summarize that research, evaluate the research relative to our model, and identify gaps in the research that could be addressed in future research.

Young children's general psychological development, functioning and adjustment.

Implementing a consistent T1D care plan is often complicated by the normal developmental characteristics of very young children and by the presence of abnormally frequent or intense problem behaviors in some children. A number of studies provide pertinent evidence.

Child temperament can influence T1D management and outcomes (51-53). In one study of 34 three to 10 year olds with T1D, higher activity and shorter attention span were associated with poorer child cooperation with daily T1D care (54).

A number of studies have evaluated the level and clinical significance of adjustment problems in YC-T1D, often concurrently with evaluations of parental psychological functioning. Wysocki et al. contributed a cross sectional study of 23 YC-T1D and their mothers (55). YC-T1D were rated as having significantly more internalizing behavior disorders (e.g. depression,

anxiety, withdrawal, somatic complaints) than the normative sample, but general behavioral maladjustment was not associated significantly with T1D-specific behavioral problems. Zenlea and colleagues' cross-sectional study of YC-T1D revealed elevated levels of affective disorder symptoms (depression, anxiety, withdrawal) in the T1D sample compared to the normative sample (56).

Given the literature discussed on temperament and psychological development in YC-T1D, as well as studies suggesting that older children with T1D and behavioral/emotional problems tend to have worse T1D outcomes and higher levels of family conflict (57), individual child characteristics are considered mediators of the relation between parental coping and T1D management behaviors in our model.

Young children's diabetes-specific behavioral problems. The T1D regimen places considerable demands on YC-T1D, including cooperation with painful and anxiety-inducing procedures (i.e., injections, finger-sticks, and insertion of pump infusion sets or continuous glucose sensors); self-regulation of eating; prevention, recognition and remediation of hypoglycemia; maintaining balance among physical activity, insulin administration, and prevailing BG levels; and self-regulation of sleep. A few studies show that YC-T1D struggle with each of these domains.

Antal et al. studied injection-related coping behaviors in 3-11 year olds with T1D using both parental report ($n = 61$) and direct observation ($n = 19$) of video recordings of routine insulin injections (58). Parents reported that 51% of these children demonstrated insulin injection distress and that this distress persisted for over one year in 30%. Younger children exhibited

significantly more distress than did older children. A few small studies support behavioral interventions for improving older children's self-injection of insulin (59-61) , but there are no studies of parent training to promote tolerance of insulin injections among YC-T1D. Further, we could find no studies of YC-T1D or their parents regarding tolerance of insertions of either insulin pump infusion sets or continuous glucose sensors.

Studies of mealtime behaviors of YC-T1D indicate: higher rates of mealtime behavior problems and parenting distress among YC-T1D compared to those without T1D (41); children's mealtime disruptive behavior, dietary deviations and coercive parenting behaviors were all associated with poorer glycemic control (31, 62); compared with parents of children without T1D, parents of YC-T1D demonstrated significantly more frequent parenting behaviors (i.e., a higher rate and frequency of commands to eat), which are associated with less food intake in studies of other clinical populations (45); dietary adherence and composition for intensively managed YC-T1D did not differ from that of conventionally treated YC-T1D, but mealtime behavior problems were associated consistently with poorer dietary adherence and nutritional composition (63, 64). Overall, these studies indicate that mealtimes are a significant flashpoint for these families, and that disruptive mealtime behavior and ineffective parenting strategies are associated with increased distress, poorer dietary adherence and poorer glycemic outcomes. An extensive evidence base demonstrating the efficacy of behaviorally oriented feeding interventions (65) has not appreciably impacted the care of YC- T1D and no rigorous clinical trials have been published.

Sleep disruption among older youths with T1D may be associated with suboptimal T1D outcomes (66), but only one study of sleep in YC-T1D was found. In that study, more child bedtime resistance and insomnia were associated with increased parent distress, anxiety, and depression and with use of an intensified insulin regimen (50). Just as mealtimes can represent a flashpoint for families of YC-T1D, children's sleep quality and quantity may be another source of T1D-related distress.

Another challenging aspect of YC-T1D care is balancing carbohydrate intake and insulin dosing with the child's activity. No studies have addressed this aspect of family management of YC-T1D. Children with highly variable physical activity may pose difficult management challenges and elevated risk of hypoglycemia.

Taken together, our model proposes that diabetes-specific behavioral problems have direct effects on T1D management and outcomes, and may be impacted by specific parental coping strategies. For example, a parent who exhibits a coercive parenting style may in turn have a child who exhibits a higher level of mealtime disruptive behavior which is associated with poorer glycemic control.

Existing Interventions

Several interventions for YC-T1D have been examined targeting parental coping with affective, behavioral, and cognitive challenges, based on presumed direct effects on parent functioning and indirect effects on child behavior and T1D outcomes. Two small trials, a social support intervention through parent mentors (67) and a coping skills training group (68) did not yield significant treatment effects. However, participants in the social support intervention

reported receiving informational support (e.g., tips for travel, school, parties and family get-togethers, camp resources, and how to advocate for the child) and affirmational support by sharing stories and validating parents' feelings and experiences. The coping skills intervention yielded significant improvements in parental coping and quality of life in both the coping skills and educational control groups, indicating that group interventions (i.e., social support) may be effective regardless of the content. Two pilot studies, a telephone-based supportive intervention for parents of YC-T1D (69) and a mealtime behavioral plus nutrition intervention for parents of YC-T1D (70), showed promising results with significant decreases in parenting stress (69), daily BG levels, and problematic parent and child mealtime behaviors (70). Supportive and group interventions may assist parents with the daily hassles of managing T1D, leading to improvement in parent functioning. Future research is needed to test whether such interventions have indirect effects on health outcomes in YC-T1D.

Research Gaps

The development of a theoretically driven model of YC-T1D management and outcomes represents progress in the growing literature on this special population. Our model extends the literature by identifying measureable influences on T1D management and outcomes that are viable targets of intervention. The development of this model is intended to inform the YC-T1D literature by providing a framework to drive future research. First, additional research on demographic influences could guide development and tailoring of interventions for certain populations. Second, since T1D management in YC-T1D relies solely on caregivers, additional research on the specific mechanisms by which these caregivers manage T1D in youth is needed.

Aside from mealtime behaviors (i.e., disruptive child mealtime behaviors and ineffective parenting strategies), there is no research on effective or ineffective strategies used in managing YC-T1D. Third, randomized controlled trials of targeted interventions for YC-T1D and their caregivers are necessary to identify the most effective strategies for improving management of YC-T1D. There are several reasonable intervention strategies for the YC-T1D population. Parent-to-parent support groups and parental coping skills training have had some initial efficacy (65-68), but continued evaluation is necessary to determine their impact on T1D outcomes. Behavioral parent training interventions have a high degree of empirical support (71) and could be tailored to specifically target T1D-specific behavioral problems typical of this population. Finally, mobile-health and social media applications designed by and for this group of parents may address common barriers to helping YC-T1D parents develop social support networks that offer timely, pertinent and helpful informational and affective supports.

Conclusions

The YC-T1D population is growing and this developmental period poses unique barriers to effective T1D management. We proposed a conceptual model linking individual parent characteristics, parental coping, and individual child characteristics to YC-T1D management and outcomes and reviewed pertinent literature. Although some intervention pilot studies show promising results, improvements in YC-T1D management and outcomes remain understudied. There are many barriers to behavioral intervention research with YC-T1D including: the small clinical population, likelihood of having other young children, challenges of transporting young

children, and the changing developmental characteristics and needs of young children. Larger, multi-center studies are needed to yield evidence-based intervention strategies for these families.

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