Youth With Type 1 Diabetes Taking Responsibility for Self-Management: The Importance of Executive Functioning in Achieving Glycemic Control

Results From the Longitudinal DINO Study

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OBJECTIVE

Successful self-management of type 1 diabetes requires cognitive skills such as executive functioning (EF). In the transition to adolescence, youth take over responsibility for diabetes management. We set out to test: *1*) the association between EF and glycemic control over time and *2*) whether this association was moderated by: *a*) youth, shared, or parent responsibility for diabetes management and *b*) youth's age.

RESEARCH DESIGN AND METHODS

Within the Diabetes IN DevelOpment study (DINO), parents of youth with type 1 diabetes (8–15 years at baseline; *N* = 174) completed a yearly assessment over 4 years. Glycemic control (HbA_{1c}) was derived from hospital charts. Youth's EF was measured using the Behavior Rating Inventory of Executive Functioning (BRIEF)-parent report. The Diabetes Family Responsibility Questionnaire (DFRQ)-parent report was used to assess diabetes responsibility (youth, shared, and parent). Linear generalized estimating equations were used to analyze data including youth's sex, age, and age of diabetes onset as covariates.

RESULTS

Relatively more EF problems are significantly associated with higher HbA_{1c} over time (β = 0.190; *P* = 0.002). More EF problems in combination with less youth responsibility (β = 0.501; *P* = 0.048) or more parental responsibility (β = −0.767; *P* = 0.006) are significantly associated with better glycemic control over time. Only age significantly moderates the relationship among EF problems, shared responsibility, and glycemic control (β = −0.024; *P* = 0.019).

CONCLUSIONS

Poorer EF is associated with worse glycemic control over time, and this association is moderated by responsibility for diabetes management tasks. This points to the importance of EF when youth take over responsibility for diabetes management in order to achieve glycemic control.

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CLIN CARE/EDUCATION/NUTRITION/PSYCHOSOCIAL

Effective self-management of type 1 diabetes in adolescent years is important to prevent diabetes-related complications later in life (1,2). This concerns a complex combination of self-regulatory tasks that are particularly challenging for youth in transition to adolescence due to hormonal changes that cause insulin resistance and psychosocial growth in the context of family and peer relationships (1). Daily self-management requires planning and correct and timely execution of tasks, which are difficult in general and more so in the face of daily hassles of (pre)puberty. Execution of these tasks demands higher-order cognitive skills with a prominent role for executive functioning (EF) (3). EF encompasses cognitive skills such as problem solving, goal setting, planning, organizing, initiating, being flexible, and self-regulation of behavior and emotions (4,5). The development of EF occurs in spurts from infancy on and is not fully developed until midadolescence or early adulthood (6). The range of age-appropriate development of EF is broad, even within a nonclinical population. Thereby, youth with type 1 diabetes might experience subtle deficits in EF compared with healthy peers, in particular youth with early-onset diabetes (before the age of 7 years), long disease duration, repeated episodes of severe hypoglycemia, and/or prolonged poor metabolic control (e.g., chronic hyperglycemia and diabetic ketoacidosis) (7–9). In adolescence, lower EF negatively affects quality of life and the ability to effectively execute self-management tasks (10). Therefore, youth with type 1 diabetes in their early and midadolescence might demonstrate vulnerabilities in their cognitive skills that could interfere with the independent management of complex diabetes tasks (11).

As children grow older, responsibilities for diabetes management tasks transfer from parents to youth, driven by biological, psychological, cognitive, and social developmental changes (11–14). For many, this may result in deterioration of glycemic control (15,16). More shared and parent responsibility of diabetes tasks throughout adolescence seems associated with better diabetes outcomes (13,15,17–20). In contrast, separation from parents, forming a personal identity, and maturation of EF are key developmental tasks. Therefore, the "negotiation" between parents and children around distribution of responsibility for diabetes management tasks is (either consciously or unconsciously) ongoing. Literature shows that parents take less responsibility when youth get older in age and pubertal status (14). Interestingly, a recent study suggests that parents' EF may compensate for EF problems of their youth to enhance treatment adherence and glycemic control (21). This might imply that for those youth with lower EF, parents may need to maintain their responsibility longer to achieve better glycemic control.

To date, the relationship among EF, diabetes management, and glycemic control in youth with type 1 diabetes has mainly been tested in cross-sectional studies and suggests a negative association (3,10,22–24). However, there is some inconsistency across these studies, and effect sizes are small to medium. The few longitudinal studies that examined cognitive functioning obtained follow-up data up to 24 months after baseline and showed that lower EF was related to worse self-management and glycemic control (24,25). Also, various studies only examined children aged 9 to 11 years, whereas diabetes management tasks at that age are often (partly) executed by parents. More longitudinal research including youth with a broad age range is needed to disentangle the relationship between EF and glycemic control in the transition to adolescence, and the role of responsibility for diabetes management should be considered in this relationship (10,11,22).

The aim of this study was to examine the longitudinal association between EF and glycemic control in youth with type 1 diabetes and possible moderation by responsibility for diabetes management and youth's age. We examined a conceptual model drawn from the biopsychosocial model based on Holmbeck and Sherpa (26). Based on literature, we hypothesized that lower EF (i.e., more problems) is associated with worse glycemic control over time in youth with type 1 diabetes. Secondly, we expected more shared or more parent responsibility to mitigate this association.

More specifically, we hypothesized that lower EF is related to worse glycemic control over time, especially in families in which youth take most responsibility for diabetes management. In families in which responsibilities are shared or parents are mainly responsible, the relationship between low EF and worse glycemic control is expected to be weaker. Finally, we hypothesized that youth's age moderates this association over time in such a way that for older youth with lower EF, more shared responsibility (as opposed to complete transfer of responsibility to youth) is associated with better glycemic outcomes. By sharing responsibility, parents may still be able to compensate for vulnerabilities in EF while also giving room for age-appropriate autonomy in management of diabetes.

RESEARCH DESIGN AND METHODS

Diabetes IN DevelOpment (DINO) is a longitudinal, multicenter, cohort study examining psychosocial, neuropsychological, and biological development of youth with type 1 diabetes in the Netherlands (26). In total, 174 youth aged 8–15 years and their parents were included at baseline. Data were collected every year over 4 years (T0 in 2013–2014 to T3 in 2016–2017). At T0, 174 parents participated, and 173 of them completed questionnaires (99.4%); at T1, 173 parents participated, and 160 completed questionnaires (92.5%); at T2, 161 parents participated, and 137 completed questionnaires (85.1%); at T3, 142 parents participated, and 110 completed questionnaires (77.5%). The flow chart in Fig. 1 shows the number of participants over time and completed parental questionnaires used in current study. Questionnaires were completed by parents online or (in case of nonresponse) on paper. Parents and youth (≥12 years) gave their written informed consent prior to study participation. The DINO study was approved by the medical ethical committee of VU University Medical Center.

Measures

Demographic and Diabetes-Related Characteristics

Hemoglobin A_{1c} (HbA_{1c}) at the last visit before the assessment and age of diabetes onset were derived from hospital charts. Demographic characteristics were self-reported.

EF

The parent-reported Behavior Rating Inventory of Executive Functioning (BRIEF) was used to assess youth's EF (4,27). This

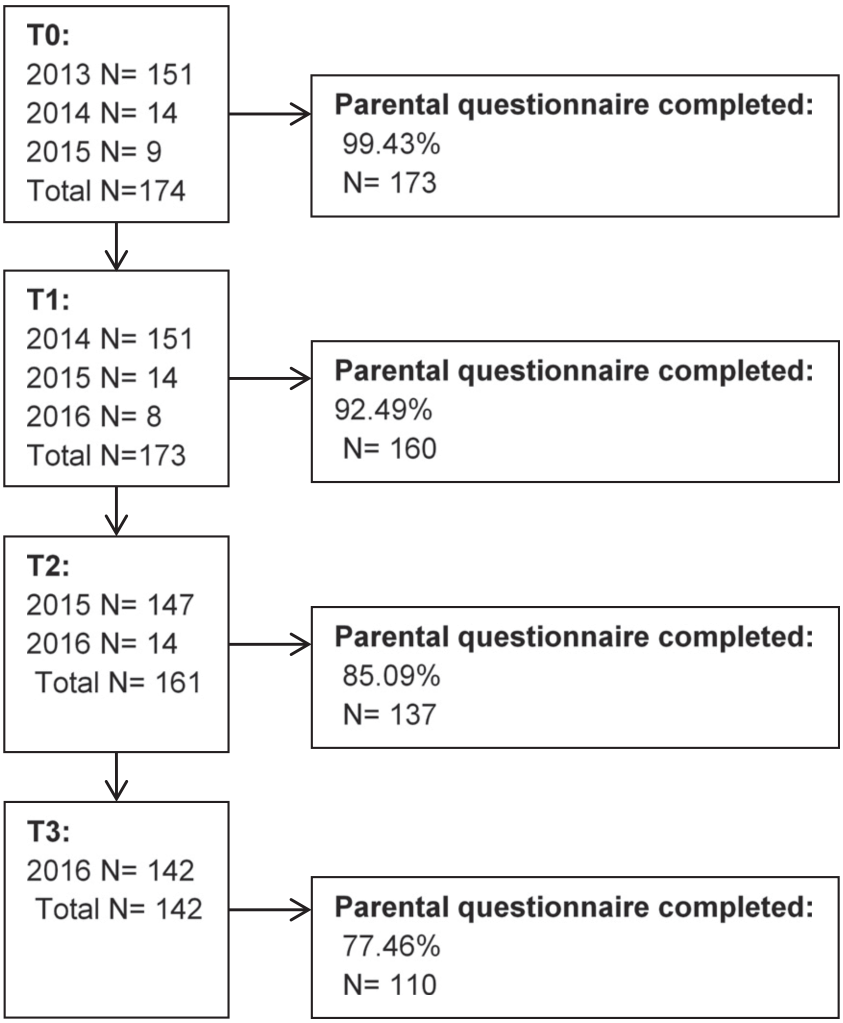

Figure 1—Flow chart of participants over time.

86-item questionnaire assesses if youth express certain behaviors on a 3-point Likert scale (never, sometimes, or often scored as 1, 2, and 3, respectively). Higher scores indicate more EF problems. T scores are corrected for age and sex, and a score ≥65 is considered clinically elevated. The global executive composite score (total score) consists of a behavioral regulation index (e.g., the ability of a child to shift cognitive set, inhibit behavioral responses, and control emotions) and a metacognition index (e.g., the ability of a child to initiate, plan, organize, monitor, and use their working memory). Psychometric properties in terms of validity and reliability of the BRIEF are satisfactory (4). In this study, high internal consistency at baseline was found for the global executive composite (Cronbach α = 0.96), behavioral regulation index (Cronbach α = 0.94), and metacognition index (Cronbach α = 0.96).

Responsibility for Diabetes Management Tasks

The Diabetes Family Responsibility Questionnaire (DFRQ) was used to examine distribution of responsibilities for diabetes tasks (28). Parents completed this 17-item questionnaire with the response options "my child takes (almost always) responsibility," "my child and I share responsibility" and "I or the other parent take (almost always) responsibility" (scored as 1, 2, and 3, respectively). In accordance with recent studies (13,15,20), we calculated percentages of youth, shared, and parent responsibility to account for different responsibility attributions. Internal consistency in the current study at baseline was high (Cronbach α = 0.88).

Statistical Analyses

Raw scores of the BRIEF (global executive composite, behavioral regulation index, and metacognition index) and the DFRQ (youth, shared, and parent responsibility) were standardized into Z scores by using the mean and SD of the baseline scores of the whole study sample (24,29). Linear generalized estimating equations with an exchangeable correlation structure were used to examine the relationship between EF and HbA_{1c} over time and the moderation of responsibility and age. Youth's age was added as a continuous variable assuming a linear relationship. Age at diabetes onset and sex were included as covariates. The significance level was set at 0.05. Generalized estimating equations use all available longitudinal data in analyses, adjust for the correlation between repeated measurements within one participant, and are able to handle participants with varying numbers of unequally spaced observations over time. Models 1 and 2 examined the main effects of EF and responsibility on HbA_{1c} over time, respectively. Model 3 examined the two-way interactions of EF and responsibility on HbA_{1c} over time. In model 4, the three-way interactions with youth's age were assessed to investigate if the relationship among EF, responsibility, and HbA_{1c} was different for younger or older youth based on median age (13.75 years).

RESULTS

In Table 1, demographic characteristics of participants at baseline (T0) are described. The mean age of participants was 12.12 ($\pm$ 2.17) years and sex was distributed equally. Mean HbA_{1c} was 7.93% ($\pm$ 1.09) or 63.21 mmol/mol ($\pm$ 11.94), and mean age at diabetes onset was 6.56 ($\pm$ 3.72) years. At baseline, mean T scores of global executive composite were 49.26 ($\pm$ 9.85), and 5.8% (N = 10) were considered clinically elevated. T scores of the behavioral regulation index (49.26 $\pm$ 9.95) and metacognition index (49.52 $\pm$ 9.76) were in line with results of the global executive composite at baseline.

Models 1 and 2 examined main effects of EF problems and responsibility on HbA_{1c} over time, respectively (Table 2). Higher global executive composite (β = 0.190; P = 0.002), behavioral regulation index (β = 0.114; P = 0.031), and metacognition index (β = 0.215; P = 0.001) scores were all significantly associated with higher HbA_{1c} values over

Table 1—Demographic characteristics of participants at baseline (T0)

	% (*n*)	Mean ± SD
Youth's age (years)	—	12.12 ± 2.17
Youth's sex (female)	50 (87)	—
Youth's age at diabetes onset (years)	—	6.56 ± 3.72
HbA_{1c} % (mmol/mol)	—	7.93 ± 1.09 (63.21 ± 11.94)
Insulin regimen		
Insulin pump	77 (134)	—
Multiple daily injections	22.4 (39)	—
Parents' descent (Dutch)	94.2 (162)	—
Parents' education level*		
Low	10.4 (18)	—
Moderate	23.1 (40)	—
High	64.7 (112)	—
NA	0.6 (1)	—
BRIEF		
Global executive composite (72–216)**	—	120.01 ± 24.75
Behavioral regulation index (28–84)**	—	42.21 ± 10.51
Metacognition index (44–132)**	—	77.80 ± 16.90
DFRQ (17–51)**	—	35.45 ± 6.29

NA, not available. *Low: primary school, lower general education (Lager BeroepsOnderwijs [LBO]); moderate: lower secondary (vocational) education (Middelbaar Algemeen Voortgezet Onderwijs [MAVO], Middelbaar Beroeps Onderwijs [MBO]); high: higher secondary education and professional education (Hoger Algemeen Voortgezet Onderwijs [HAVO], Voorbereidend Wetenschappelijk Onderwijs [VWO], Hoger Beroeps Onderwijs [HBO], and university). **Raw scores.

pronounced in youth with high own responsibility and low parental responsibility for management tasks. Figure 2*A* and *B* illustrate the pattern of the two-way interaction effect (30). It shows that high EF problems in youth with high own responsibility (Fig. 2*A*) or low parental responsibility (Fig. 2*B*) were associated with higher HbA_{1c} values.

In line with global executive composite, parent responsibility significantly moderated the association between both the behavioral regulation index and metacognition index on HbA_{1c} over time (β = −0.607, *P* = 0.012; and β = −0.766, *P* = 0.005, respectively). Youth responsibility did not significantly moderate these associations.

Model 4 examined the three-way interaction of EF problems, responsibility, and age on HbA_{1c} over time (Table 2). Only the relationship with age and shared responsibility was significant over time (global executive composite, β = −0.024, *P* = 0.019; behavioral regulation index, β = −0.025, *P* = 0.015; and metacognition index, β = −0.021, *P* = 0.041). When split by the median, the moderation of shared responsibility was only significant for the younger age group (β = 8.37; *P* = 0.001): younger youth with relatively more EF problems and less shared responsibility achieved lower HbA_{1c} values over time

time. This indicates that more EF problems were significantly associated with worse glycemic control over time. Neither youth nor shared or parent responsibility were significantly associated with HbA_{1c} over time.

Model 3 examined the two-way interactions of EF problems and responsibility on HbA_{1c} over time (Table 2). Youth (β = 0.501; *P* = 0.048) and parent responsibility (β = −0.767; *P* = 0.002) significantly moderated the association between global executive composite and HbA_{1c} over time. The association between more EF problems and high HbA_{1c} was most

Table 2—Unstandardized β-coefficients of the different models of the association of EF problems (global executive composite), responsibility, and age on HbA_{1c} over time

	Model 1: Main effect	Model 2: Main effect	Model 3: Two-way interaction	Model 4: Three-way interaction
EF problems				
EF problems (GEC)	0.19**			
Responsibility				
Youth responsibility		−0.25		
Shared responsibility		0.22		
Parent responsibility		−0.01		
EF problems × responsibility				
EF problems (GEC)			0.020	
Youth responsibility			0.061	
EF problems (GEC) × youth responsibility			0.501*	
EF problems (GEC)			0.437***	
Parent responsibility			−0.246	
EF problems (GEC) × parent responsibility			−0.767**	
EF problems × responsibility × age				
EF problems (GEC)				−1.798**
Shared responsibility				1.450
Age				0.010*
EF problems (GEC) × shared responsibility				4.159**
EF problems (GEC) × age				0.011**
Shared responsibility × age				−0.007
EF problems (GEC) × shared responsibility × age				−0.024*

GEC, global executive composite. *$P < 0.05$; **$P < 0.01$; ***$P < 0.001$.

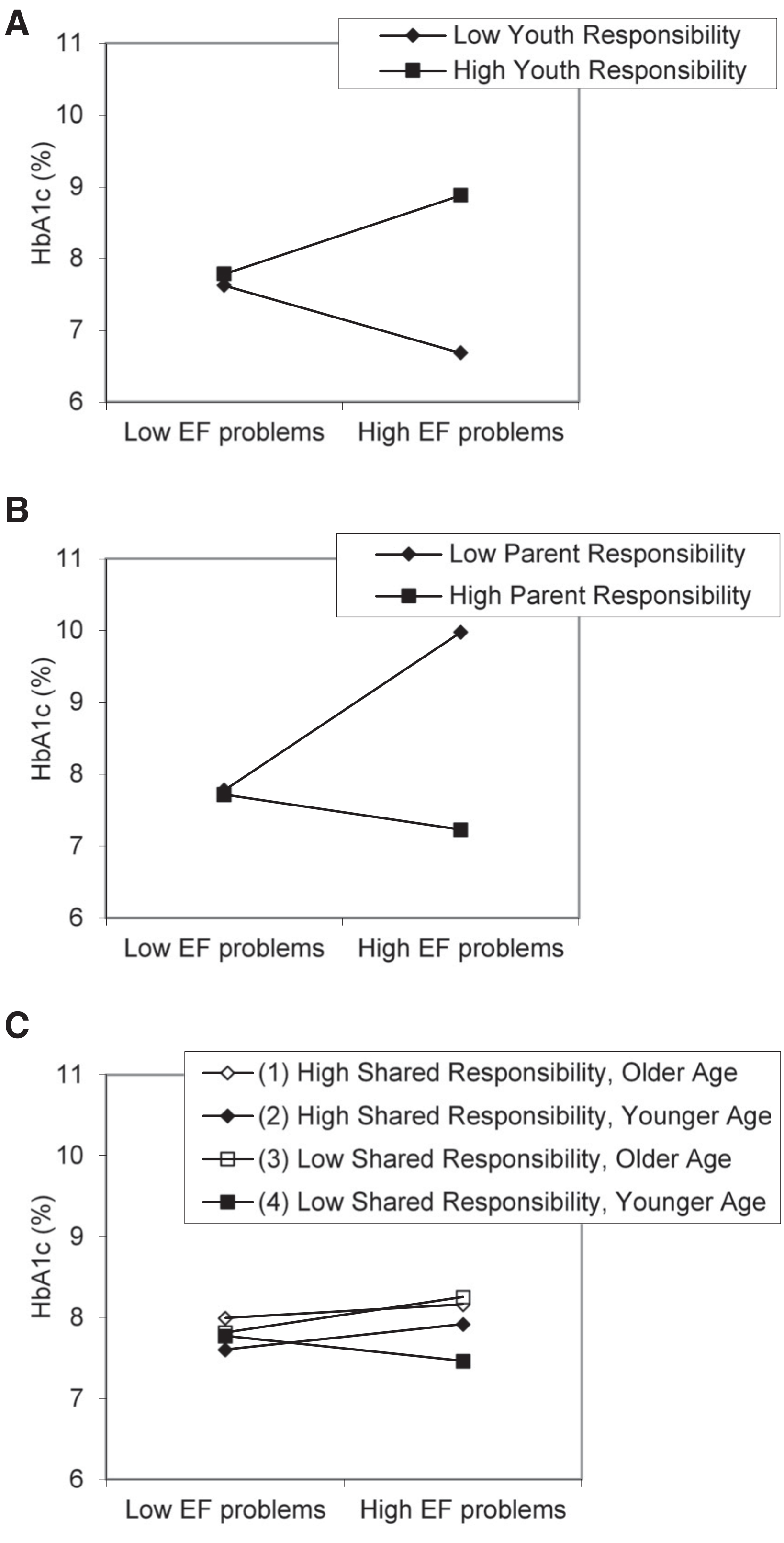

Figure 2—The pattern of significant two- and three-way interactions of EF problems, responsibility (*A*: youth, *B*: parent, *C*: shared), and age (based on median) on HbA_{1c} over time.

compared with those with more shared responsibility. Concerning the older age group, shared responsibility does not significantly affect the association between EF problems and HbA_{1c}. Figure 2*C* illustrates the pattern of the three-way interaction effect (30). For younger youth, high EF problems and high shared responsibility are associated with higher HbA_{1c}.

For youth's responsibility and parent responsibility, age did not significantly moderate the relationship among EF problems, responsibility, and HbA_{1c}.

When observing descriptive baseline data post hoc, parents were more responsible for the diabetes tasks in the younger age group (youth responsibility, 15%; shared responsibility, 37%; and parent responsibility, 48%). In the older age group, the responsibilities were mainly youth's and/or shared (youth responsibility, 38%; shared responsibility, 37%; and parent responsibility, 25%). Thus, in the transition to adolescence, responsibilities shift from mainly the parents to mainly youths. The percentage of shared responsibility seemed to be similar in the younger and older age group.

CONCLUSIONS

This study is, to the best of our knowledge, the first to show that the longitudinal relationship between EF and glycemic control in youth with type 1 diabetes is moderated by responsibility for diabetes management and age over time. Previous, mainly cross-sectional studies did not consistently show that EF and glycemic control are related (10,22,25,31). With the current study, we found a direct longitudinal relationship between EF and glycemic control. For youth with lower EF (i.e., more problems), less parent or more youth responsibility for diabetes management is associated with worse glycemic control over time. Interestingly, youth's age was only a significant moderator in the relationship among shared responsibility, EF, and glycemic control and not in the relationship with youth's or parent's responsibility. It seems that in youth with relatively low EF (i.e., more problems), parent responsibility for diabetes management remains important in the transition to adolescence, more so than shared responsibilities.

In the younger age group, low EF in combination with more shared responsibility showed a negative relationship with glycemic control over time. This indicates that transferring responsibilities for diabetes management in youth with relatively lower EF, even when it is shared, could have a detrimental effect on glycemic control when youth are in their pre- and early pubertal years. In the older age group, lower EF and shared responsibility were not significantly associated with glycemic control over time. This suggests that older youth with lower EF tend to have poorer glycemic control over time irrespective of the amount of shared responsibility.

Meanwhile, in transition to adolescence, the "negotiation" between parents and youth about the distribution of responsibility for diabetes management tasks is ongoing. Parents and youth have to find their own strategy of responsibility for diabetes management tasks, either conscious or not. Transferring responsibilities for diabetes management to youth themselves is important for social and psychological development and to increase autonomy, especially for older youth (12,15). However, our results show that parental involvement irrespective of age seems to be important to achieve optimal glycemic control, especially for youth with lower EF. Based on the biopsychosocial model we examined a direct relationship among EF, responsibility, and glycemic control. The figures seem to show a trend that youth with lower EF and less youth or more parent responsibility do better than those with higher EF. Based on our results, we were not able to test whether this was a significant effect. Further research is needed to examine this in more detail. It might indicate an inadequate strategy of dividing responsibilities for diabetes management because youth capable of executing diabetes management also require the autonomy to do so. Intervention studies would be necessary to see if changing the distribution of responsibility (i.e., more shared or parental responsibilities in youth with lower EF, throughout adolescence) would result in better glycemic outcomes over time. In this context, other factors affecting the relation among EF, responsibility, and glycemic control need to be considered as well. Conflicting perceptions of responsibility, family conflict, self-efficacy, adherence, parental EF, and psychological and emotional problems of youth and parents could all play a role (10,14,21,22,32).

In this study, lower EF was defined as relatively more EF problems compared within this cohort of youth with type 1 diabetes and not as clinically significant EF problems. The baseline T scores of lower EF in our cohort are within the range of normal functioning, and only 5.8% are considered clinically elevated. We may conclude that even subtle differences in EF within a group of youth with type 1 diabetes are relevant in the execution of diabetes-management tasks to achieve glycemic control. Therefore, further research may examine youth with and without clinically elevated deficits in EF (7–9).

Suchy et al. (23) suggest that outcomes on the BRIEF questionnaire and neuropsychological assessment are both associated with glycemic control while measuring different constructs of EF. We may question the specific role of different underlying aspects of EF on diabetes outcomes. Current results indicate that for the achievement of glycemic control, behavioral-regulation skills (such as inhibition, cognitive flexibility, and emotion regulation) are as important as metacognitive skills (such as taking initiative, planning, organizing, monitoring, and using ones' working memory). The separate index scores were not associated with youth responsibility as a moderator. However, this could be due to the borderline significance level of the total score (global executive composite) of youth responsibility and the reduced power of the index scores.

Our findings have clinical implications. For example, when considering more complex and flexible treatment options, the level of EF and youth's own responsibility should be taken into consideration. Screening for low EF in routine care can be of additional value in clinical decision-making (33,34). The International Society for Pediatric and Adolescent Diabetes guidelines of 2018 state that "routine assessment should be made of developmental adjustment" and hint at EF skills as goal setting and problem solving, but based on this study, we suggest including EF skills into routine assessments (35). A measure such as the recently developed Diabetes Related Executive Functioning Scale could be helpful in this study. In addition, an assessment of responsibility for diabetes management tasks could be integrated into the regular monitoring of quality of life and/or into a care transition protocol (36). We suggest assessing cognitive skills of youth and encourage parents and health care professionals to adjust responsibilities based on youth's skills instead of age and pubertal status (14,18). For those youth with executive dysfunction, a broad EF examination (by using the BRIEF and neuropsychological assessment) and targeted psychoeducation or neuropsychological treatment can be considered.

Our study has strengths and limitations that deserve to be mentioned. The longitudinal design, length of observation, and robust statistics are strengths of this study, adding to the internal validity. However, because we examined associations over time, we are not able reveal the direction of the effects. We managed to include and retain a relatively large sample of parents of youth with type 1 diabetes. Although we used well-validated measures, we relied on parent report. Perhaps additional self- or teacher-reported questionnaires provide a more valid assessment of EF. Also, neuropsychological assessment might be more reliable, but might tap into different aspects of EF because it captures the ability to use EF in a structured laboratory situation (37). The strength of the BRIEF questionnaire is that it reflects problems in the use of EF observed in everyday life (23).

Because the majority of our families were of Dutch origin and fairly highly educated (38), future research should aim to examine more diverse cohorts in terms of ethnicity, education, and socioeconomic status. As previous studies showed that low socioeconomic status and belonging to a minority ethnic group are associated with less optimal diabetes outcomes, study results may be more pronounced in a more diverse cohort (39,40).

In conclusion, the balance between EF skills and responsibility for diabetes management tasks is important to achieve optimal glycemic control over time in the transition to adolescence. More parent and less youth responsibility appears to buffer the negative effects of low EF and is associated with better glycemic control over time. Routine assessment of EF skills of youth with type 1 diabetes could help optimize the shift from shared or parental responsibility to youth's own responsibility and help reach optimal glycemic control in this challenging period toward adolescence.

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