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## Relationship of Youth Involvement in Diabetes-Related Decisions to Treatment Adherence

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### Abstract

The aim of this study was to examine the relationship of youth's involvement in diabetes-related decisions to adherence. Children and adolescents (8–19 years) and their parents (N = 89) completed the Decision Making Involvement Scale (DMIS) and the Self Care Inventory, a self-report measure of adherence. After controlling for youth age, the degree to which youth expressed an opinion and information to parents was associated with better parent- and youth- reported adherence. The degree to which parents expressed an opinion and information to youth was associated with worse parent-reported adherence. Joint decision-making behaviors (e.g., negotiation; provision of options) also were associated with better youth-reported adherence. Encouraging youth to express opinions and share illness-related information with parents during illness management discussions may improve adherence. Additional research is needed to identify mechanisms of effect and determine associations between decision making involvement and health behaviors and outcomes over time.

### Keywords

decision making; adherence; type 1 diabetes; children; adolescents

### Introduction

The management of type 1 diabetes (T1D) requires frequent decisions and treatment tasks that must be addressed by youth and their parents on a daily basis. Decisions must be made regarding adjusting insulin doses based on activity and/or diet, responding to symptoms of low or high blood glucose, and addressing aspects of the regimen when the youth is away

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Informed Consent: All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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from the parent. Parents assume most of the responsibility for managing these tasks and decisions when children are young but transfer this responsibility to youth gradually as they get older. This transition can be challenging for families, and adherence to diabetes treatment typically declines during adolescence (Miller & Drotar, 2007; Rausch et al., 2012; Ricker, Delamater, & Hsu, 1998). There are a variety of potential reasons for this, including lack of effective self-management skills (Modi et al., 2012) and inappropriate levels of parental involvement (Nansel et al., 2009; Wiebe et al., 2005).

The way in which parents and youth interact around decisions about the management of T1D may provide the foundation for the youths' assumption of effective illness management as they mature. In particular, youth's decision making involvement (DMI), defined as the various ways in which youth contribute to the decision making process (Miller & Harris, 2012), may enable youth to learn important skills, such as the factors to consider when making decisions, the consequences of different decisions, and how to communicate and negotiate about decisions (Miller, 2009; White, 1996; Wills, Blechman, & McNamara, 1996). In the context of T1D, such involvement may also help youth to gain specific knowledge and experience related to effective management and may also confer youth with a sense of greater control and self efficacy related to the illness (Miller, 2009; White, 1996; Wills, et al., 1996). Sharing information and ideas related to illness management may also facilitate adherence by increasing the likelihood that parents and youth are "on the same page," so that timely and effective decisions can be made (Miller, 2009). Data related to the ways in which different types of decision making involvement relate to adherence are important and will help clinicians facilitate the most appropriate levels of involvement as youth mature.

Constructs related to DMI, such as maternal collaboration in coping with diabetes stress (Wiebe, et al., 2005) and parent collaborative involvement in diabetes care (Nansel, et al., 2009), are associated with better treatment adherence. In addition, there is evidence that interventions that include a parent-child teamwork approach related to type 1 diabetes management reduce declines in metabolic control (Laffel et al., 2003; Nansel, Iannotti, & Liu, 2012). However, this prior work neglects the *process* of decision making about illness management, as well as the youth's role in the process. The concept of DMI captures *how* parents and youth interact together when making decisions about illness management and can shed light on the specific parent and youth behaviors that are most beneficial for successful illness management across development.

We developed a new measure of youth's DMI related to chronic illness management, called the Decision Making Involvement Scale (DMIS), in children and adolescents with T1D, cystic fibrosis, or asthma (Miller & Harris, 2012). The factor analysis yielded five subscales, reflecting different ways for youth to be involved in decision making: Child Express (e.g., express an opinion and give information to parent), Child Seek (e.g., ask for advice or information from parent), Parent Express (e.g., express an opinion, advice, or information to child), Parent Seek (e.g., ask for child's opinion and listen to child), and Joint/Options (e.g., negotiate together; parent provision of options to child).

The present report is based on a secondary analysis of that dataset. The purpose of the analyses reported here was to test associations of DMIS scores with treatment adherence in the subset of participants with T1D. Our primary hypothesis was that more decision making involvement would be associated with better adherence, after controlling for youth age. Specifically, we expected that higher scores on each of the five DMIS subscales would be associated with better adherence.

## Methods

### Recruitment

Recruitment took place from June 2008 through May 2010 at an urban, tertiary care pediatric hospital in the northeastern United States. Youth and parents were eligible if the youth was between the ages of 8 and 19 years and had a diagnosis of T1D, asthma, or cystic fibrosis for at least six months. We also required that the parent and youth could identify a discussion they had related to illness management in the prior two weeks, which is necessary for completion of the DMIS. Potential participants were identified from outpatient clinic schedules and inpatient census data and contacted by telephone or in person about the study. Of the 226 evaluable participants in the larger study (Miller & Harris, 2012), the present analysis is limited to the 89 youth participants with type 1 diabetes and their parents (one parent per child) with complete data for the variables of interest.

### Procedures

The study was approved by the institutional review board and procedures were in accordance with international guidelines for the ethical conduct of human subjects research. A member of the research team explained the study to the parent and youth. After consent and assent were obtained, a member of the research team reviewed each questionnaire with the parent and youth separately. Each youth and parent participant received \$20 after completing the questionnaires (\$40 total per dyad).

### Measures

**Decision Making Involvement Scale (DMIS)**—The development of the DMIS was the primary purpose of the larger study on which this analysis is based (Miller & Harris, 2012). To administer the DMIS, a member of the research team assisted the dyad in identifying a discussion they had about chronic illness management in the last two weeks. Dyads were first asked if they talked about diabetes in the last two weeks; if they answered yes, they were asked what the discussion was about. If they answered no, the interviewer said, “There are discussions you might have had that seem routine, such as whether to check blood glucose or how much insulin to inject/bolus. Have you discussed any of these issues in the past two weeks?” An example of a discussion is that the parent and youth discussed how the youth would manage her diabetes prior to and during a school dance. A second example is a discussion about what to do if the youth’s blood glucose was elevated and there were ketones in his urine. Parents and youth rarely, if ever, disagreed about what discussion to identify. If one member of the dyad spoke very little (usually the youth), then the interviewer asked the youth, “Do you remember what you said or did during that discussion?”, in an effort to help the youth orient him or herself to the discussion that was

identified. Parents and youth then independently completed the items, which assess what each might have said and done during the discussion and reflect different ways for youth to be involved in decisions about illness management. The response options were Not at all (1), A little bit (2), A moderate amount (3), and A lot (4). The questionnaire yields five subscale scores, described earlier, which are the same for both parent and youth report: Child Express, Child Seek, Parent Express, Parent Seek, and Joint/Options. Higher scores indicate greater engagement in the target behavior during the discussion. Cronbach's alphas for the five subscales in the diabetes sample ranged from 0.76 to 0.91 for parent report and 0.63 to 0.83 for child report (Table 1). Scores for parent and youth report on the DMIS subscales were slightly to moderately correlated and ranged from 0.23 to 0.42 using Spearman correlations. Spearman correlations among the five subscales ranged from 0.17 to 0.63 for parent report and 0.19 to 0.66 for youth report. The DMIS subscales also showed moderate to substantial test-retest reliability in the sample as a whole, and the validity of the measure was supported by associations with child age, child health locus of control, and family communication (Miller & Harris, 2012).

**Demographics**—Parents completed a demographic form that assessed characteristics of the child (e.g., age), parent (e.g., marital status), and family (e.g., income).

**Adherence**—Parents and youth ages 12 years and older ( $n = 56$ ) completed the Self Care Inventory (SCI; Greco et al., 1990), which measures adherence to the diabetes treatment regimen over the past month. The instructions ask, “In the past month, how well have you followed your treatment recommendations?” The items then consist of 14 diabetes tasks (e.g., “Glucose testing”; “Administering insulin at the right time”). Each item is rated on a 5-point scale ranging from “never do it” to “always do this as recommended without fail”. The SCI is considered a well-established measure of adherence to treatment in type 1 diabetes (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). We calculated an average score separately for parent and youth report, based on the seven items recommended by La Greca (2004). Cronbach's alpha was 0.80 for parent report and .78 for youth report in the present sample. Parent and youth scores on the SCI were correlated at 0.58 ( $p < .0001$ ). Higher scores indicate better adherence.

### Data Analytic Plan

Bivariate associations between DMIS and adherence scores were examined first using Spearman's rho correlation coefficients and are presented in Table 2. The primary hypotheses testing associations between the DMIS subscales and adherence scores were examined using multiple regression analysis. Four regression models were defined, predicting adherence. Two of the models included parent report of adherence as the dependent variable ( $n = 89$ ) and either the five parent-report DMIS subscales or five youth-report DMIS subscales as independent variables. The other two models included youth report of adherence as the dependent variable ( $n = 56$ , ages 12–19 years only) and either the five parent-report DMIS subscales or five youth-report DMIS subscales as independent variables. Youth age was included as an independent variable in all models. Other demographic variables such as child sex, duration of diagnosis, family income, and parent highest education were examined as potential predictors/covariates in the regression models,

but none were associated with adherence in this sample. Variable selection for the final models utilized the stepwise selection procedure. Model assumptions, residual tests, diagnostic plots, and the presence of multicollinearity were examined prior to reporting the final models.

## Results

### Participants

Demographic characteristics of the sample are presented in Table 3. Mean SCI scores were 3.80 ( $SD = .68$ , range: 2.29–5.00) for youth report and 3.93 ( $SD = .70$ , range: 2.00–5.00) for parent report, indicating that, for the sample as a whole, diabetes management tasks were usually completed, with occasional lapses.

### Description of DMIS Discussions

The most frequent type of discussion that was identified by dyads had to do with the youth's routine treatment regimen, such as how much insulin to inject or whether to check blood glucose ( $n = 58$ ; 64%). The next most frequent categories had to do with activities and their impact on treatment ( $n = 10$ ; 11%) and dealing with symptoms ( $n = 10$ ; 11%). Additional categories were interactions with the health care system ( $n = 6$ ; 7%) and changing the treatment regimen ( $n = 6$ ; 7%).

In response to a question about how typical the parent-youth discussion was compared to other discussions they had about diabetes in the last two weeks, 77% of parents and 71% of youth responded "A moderate amount" or "A lot," suggesting that the discussions were generally representative of other recent discussions about illness management.

### Relationship of Decision Making Involvement to Adherence

Models were carefully examined for model assumptions, residual tests, diagnostic plots, and the presence of multicollinearity. The final selected regression models are presented in Table 4. Older youth age was associated with worse adherence in all four models. In the first model, parent report of more Child Express was associated with better parent-reported adherence; the final model accounted for 36% of the variance in adherence scores. In the second model, youth report of more Child Seek and less Parent Express was associated with better parent-reported adherence; the final model accounted for 31% of the variance in adherence scores. In the third model, parent report of more Child Express was associated with better youth-reported adherence; the final model accounted for 28% of the variance in adherence scores. In the fourth model, youth report of more Joint/Options was associated with better youth-reported adherence; the final model accounted for 29% of the variance in adherence scores. Neither youth nor parent report of Parent Seek were associated with adherence scores in any of the models.

## Discussion

The present study adds to the existing body of work related to family management of T1D by demonstrating associations of specific youth decision making behaviors with adherence.

Specifically, parents' perceptions of the extent to which youth expressed opinions and information during the discussion were associated with both parent and youth report of adherence after accounting for youth age. In addition, youths' perceptions of the extent to which they sought opinions and information from parents were associated with parent-reported adherence. One potential explanation is that when youth share information and opinions (e.g., telling the parent that he or she feels "low" or suggesting a specific insulin dose/bolus), parents may be better able to provide appropriate feedback and assist with timely management of symptoms. The importance of youth disclosure has been supported in the developmental literature (Kerr & Stattin, 2000) but has not been examined systematically in the context of chronic illness management (Ellis, Templin, Naar-King, & Frey, 2008). However, one recent study did find that more disclosure was associated with more parental knowledge and better adherence and that greater secrecy was associated with worse adherence and metabolic control, in adolescents with T1D (Osborn, Berg, Hughes, Pham, & Wiebe, 2012).

Youth report of joint decision making, which included negotiating, brainstorming, and provision of options by parents, was also associated with better youth-reported adherence. This finding is consistent with prior research on related constructs, such as maternal collaboration in coping with diabetes stress and parent collaborative involvement in diabetes care, which are associated with better adherence, metabolic control, and quality of life (Nansel, et al., 2009; Wiebe, et al., 2005). Working through problems and decisions with parents provides youth with the opportunity to learn decision-making skills and have a voice in the process, with the parent still present as a source of support and guidance. This type of involvement may empower youth to engage in more effective illness management. However, more research is needed to identify the mechanisms through which specific types of decision-making involvement may influence adherence and whether these associations change across development.

While youth who *sought* information and advice from parents were more adherent, parents who *gave* information and advice to youth had youth who were less adherent. This finding was surprising, because different aspects of parental involvement have been associated with better adherence in multiple studies in T1D (Berg et al., 2011; Nansel, et al., 2009; Palmer et al., 2004; Wiebe, et al., 2005). However, the nature of parental involvement and children's appraisals of that involvement may be critical factors in determining the benefits with respect to health behaviors and outcomes. For example, prior qualitative research found that adolescents with well-controlled diabetes appraised parental monitoring more positively compared to those with worse control, who tended to describe parental monitoring as annoying (Leonard, Garwick, & Adwan, 2005). In addition, the DMIS measures specific parental behaviors related to giving and seeking advice and information, which is a narrower focus compared to measures of parental involvement, which assess task-related assistance and emotional support (e.g., the Collaborative Parent Involvement Scale, Nansel, et al., 2009). Another possible explanation for the finding that Parent Express was associated with worse adherence is that parents provide more guidance when they perceive that the youth is non-adherent.

These findings should be interpreted in light of several limitations. First, the study design was cross-sectional, so we cannot determine the direction of the relationship between the decision making involvement and treatment adherence. For example, it is possible that when adherence is better, youth feel more comfortable sharing information with parents. Furthermore, active engagement in decision making may simply be a proxy for overall commitment to the treatment regimen. Second, we relied on self-reports of adherence and did not include an objective assessment, such as blood glucose meter data. As such, ratings of adherence may be overly optimistic (Modi et al., 2006). Third, the DMIS has some limitations, including that it allows for the identification of different types of discussions and decisions related to illness management, which may have different implications for adherence (Angst & Deatrick, 1996). In addition, it is based on a single sample of behavior identified by the dyad, which may not be reflective of how youth and parents typically communicate about diabetes management issues. However, the majority of participants indicated that the discussion was typical of other recent discussions. Fourth, our sample may not be representative of families with higher levels of conflict or low overall engagement with one another about diabetes management (Miller & Harris, 2012). Such families may have declined to participate in the study or may have been ineligible, because we required that dyads had a discussion about illness management in the last two weeks. Fifth, our participants were primarily Caucasian and mothers, and the extent to which the findings are generalizable to more ethnically diverse samples and fathers is unknown. Finally, we did not collect information about metabolic control (i.e., HbA1C) of the youth participants.

The clinical implications of these findings include encouraging youth to share opinions and information about diabetes management issues (e.g., identifying and managing symptoms of low blood glucose; the decision about switching to an insulin pump). Doing so not only shows respect for the youth's role in illness management, but also is likely to facilitate more timely and effective illness management. If there are barriers to youths' ability to share information and opinions with parents, clinicians can help families to recognize these barriers and identify strategies for overcoming them. These findings also provide further support for the promotion of joint illness management between parents and youth (Laffel et al., 2003; Nansel, Iannotti, & Liu, 2012).

Future research should examine whether youth decision making involvement predicts adherence and treatment responsibility over time. For example, longitudinal research can help to determine if there are early patterns of interacting that are most beneficial for adherence and the assumption of greater responsibility for the regimen as the child matures. Such research is currently underway and will also consider how to utilize the DMIS in a way that does not require examination of five distinct subscales for each reporter (e.g., collapsing all youth behaviors into one subscale and all parent behaviors into one subscale). However, to the extent that the subscales are differentially associated with age and adherence, for example, collapsing scores may not be conceptually appropriate. Additional research is also needed to understand the nature of youths' diabetes-related disclosures in more depth. Our measure, the DMIS, assesses the extent to which youth shared information and opinions with parents in a discussion about illness management. We still know very little about the factors that facilitate or impede youths' disclosures about specific illness-related issues, as

well as the reasons for and consequences of lying and failing to disclose diabetes-related information to parents (Ellis, et al., 2008; Hafetz & Miller, 2010).

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**Table 1**

## DMIS Characteristics

DMIS subscales and item examples (from both parent- and youth-report forms)	# of items	$\alpha$ child report	$\alpha$ parent report
Child Seek	3	.83	.91
<ul style="list-style-type: none"> <li>• My child asked me for information</li> <li>• I asked my mom/dad for information</li> <li>• My child asked questions</li> <li>• I asked my mom/dad questions</li> </ul>			
Child Express	3	.77	.76
<ul style="list-style-type: none"> <li>• My child expressed an opinion</li> <li>• I expressed an opinion</li> <li>• My child suggested ideas</li> <li>• I suggested ideas</li> </ul>			
Parent Seek	4	.72	.80
<ul style="list-style-type: none"> <li>• I listened to what my child had to say</li> <li>• My mom/dad listened to what I had to say</li> <li>• I asked my child for information</li> <li>• My mom/dad asked me for information</li> </ul>			
Parent Express	5	.63	.83
<ul style="list-style-type: none"> <li>• I gave my child information</li> <li>• My mom/dad gave me information</li> <li>• I expressed my opinion</li> <li>• My mom/dad expressed his/her opinion</li> </ul>			
Joint/Options	5	.76	.76
<ul style="list-style-type: none"> <li>• I explained different options about what to do</li> <li>• My mom/dad explained different options about what to do</li> <li>• We negotiated</li> </ul>			

Abbreviations: DMIS= *Decision Making Involvement Scale*

**Table 2**

**Bivariate Correlations among Age, Adherence, and Decision Making Involvement**

Variable	1	2	3	4	5	6	7	8
1. Youth age	-	-.51***	-.38**	-.17	.21*	-.03	-.10	-.22*
2. Adherence (parent report)	-.51***	-	.58***	.34**	.05	.17	-.05	.22*
3. Adherence (youth report, age 12–19 years)	-.38**	.58***	-	.26	.14	.23	.10	.43**
4. DMIS: Child seek	-.11	.35**	.28*	-	.55***	.66***	.42***	.58***
5. DMIS: Child express	.03	.33**	.27*	.55***	-	.63***	.19	.38***
6. DMIS: Parent seek	-.09	.25*	.17	.51***	.49***	-	.42***	.61***
7. DMIS: Parent express	-.28**	.15	.01	.38***	.17	.51***	-	.60***
8. DMIS: Joint/options	-.27*	.11	-.05	.46***	.29**	.63***	.62***	-

Note. Correlations are based on Spearman-rho. For rows and columns 4–8, correlations above the diagonal are for youth report of DMIS subscales, and correlations below the diagonal are for parent report of DMIS subscales.

Abbreviations: DMIS= *Decision Making Involvement Scale*

\*  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .0001$

**Table 3**

## Demographics

<b>Variable</b>	<b><i>n</i> (%) or <i>M</i> (<i>SD</i>)</b>
Child age	13.61 (3.20)
Parent age	43.64 (7.70)
Child sex (female)	52 (58)
Parent sex (female)	79 (88)
Child race	
White	70 (78)
African-American/Black	16 (18)
Asian	2 (2)
Amer. Indian/Alaskan Native	0
Other	2 (2)
Parent education	
Some high school	1 (1)
Completed high school	12 (13)
Some college or technical school	32 (36)
College graduate	30 (33)
Some post-graduate education	5 (6)
Masters, PhD, MD, law degree	10 (11)
Family structure	
Two parents	77 (86)
Single parent	13 (14)
Illness duration (years)	5.62 (3.95)

**Table 4**  
 Stepwise Multiple Regression Results for Effects of Age and DMIS Subscales on Adherence

Models	F	B	$\beta$	95% CI for B	Adj. R <sup>2</sup>	F	B	$\beta$	95% CI for B	Adj. R <sup>2</sup>
Dependent Variable: Parent-reported adherence (n = 89)										
Youth age	25.42***	-.11	-.50***	-.15, -.07	.36	11.49***	-.17	-.50**	-.25, -.09	.28
DMIS subscales (parent report)										
Child express		.31	.36***	.16, .45			.31	.40**	.12, .49	
Parent seek		--	--	--			--	--	--	
Parent express		--	--	--			--	--	--	
Child seek		--	--	--			--	--	--	
Joint/Options		--	--	--			--	--	--	
Dependent Variable: Youth-reported adherence (n = 56) <sup>^</sup>										
Youth age	14.02***	-.10	-.45***	-.14, -.06	.31	12.12***	-.13	-.38**	-.21, -.05	.29
DMIS subscales (youth report)										
Child seek		.26	.33**	.10, .41			--	--	--	
Child express		--	--	--			--	--	--	
Parent seek		--	--	--			--	--	--	
Parent express		-.23	-.21*	-.46, -.01			--	--	--	
Joint/Options		--	--	--			.37	.40**	.16, .58	

Note.

\* p < .05,

\*\* p < .01,

\*\*\* p < .0001

<sup>^</sup> age 12–19 years only

-- in the stepwise regression, these variables were not significantly associated with the dependent variable in prior steps and, therefore, were excluded from the final model

Abbreviations: DMIS= *Decision Making Involvement Scale*