

# Responsibility Sharing between Adolescents with Type 1 Diabetes and Their Caregivers: Importance of Adolescent Perceptions on Diabetes Management and Control

Anthony T. Vesco,<sup>1</sup> BA, Barbara J. Anderson,<sup>2</sup> PhD, Lori M. B. Laffel,<sup>3</sup> MD, MPH, Lawrence M. Dolan,<sup>4,5</sup> MD, Lisa M. Ingerski,<sup>1</sup> PhD, and Korey K. Hood,<sup>1,5</sup> PhD

<sup>1</sup>Center for the Promotion of Treatment Adherence and Self-Management, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, <sup>2</sup>Department of Pediatrics, Baylor College of Medicine/Texas Children's Hospital, <sup>3</sup>Pediatric, Adolescent, and Youth Adult Section, Joslin Diabetes Center, Harvard Medical School, <sup>4</sup>Diabetes Center, Division of Endocrinology, Cincinnati Children's Hospital Medical Center, and <sup>5</sup>Department of Pediatrics, University of Cincinnati College of Medicine

All correspondence concerning this article should be addressed to Korey K. Hood, PhD, Center for the Promotion of Treatment Adherence and Self-Management, Cincinnati Children's Hospital Medical Center, MLC 7039, 3333 Burnet Avenue, Cincinnati, OH, 45229, USA. E-mail: korey.hood@cchmc.org

Received October 5, 2009; revisions received April 2, 2010; accepted April 8, 2010

**Objective** To analyze associations between factor scores for caregiver responsibility for direct and indirect diabetes management tasks with glycemic control and blood glucose monitoring (BGM) frequency.

**Methods** Two hundred and sixty one adolescents with type 1 diabetes and their caregivers completed the Diabetes Family Responsibility Questionnaire (DFRQ). Data on diabetes management (e.g., BGM frequency) and glycemic control (e.g., A1c values) were obtained. **Results** Confirmatory factor analysis of the DFRQ revealed two factors—direct and indirect management tasks. Multivariate analyses demonstrated that adolescent perception of greater responsibility sharing with caregivers on direct management tasks was significantly associated with higher BGM frequency. **Conclusions** Adolescents who perceive greater caregiver responsibility, particularly around direct management tasks, engage in better diabetes management. Implications of these findings include designing interventions that encourage and sustain caregiver responsibility through adolescence and make explicit the contribution of caregivers.

**Key words** adolescents; family; glycemic control; responsibility sharing; type 1 diabetes.

## Introduction

The management of pediatric type 1 diabetes requires the daily execution of a complex and demanding set of health behaviors. These behaviors include the coordination of the amount and timing of insulin administration with results of blood glucose monitoring (BGM), the amount and type of dietary intake, and the frequency and intensity of physical activity (e.g., Silverstein et al., 2005). Families play a central role in the supervision and management of type 1 diabetes (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Hanson, Henggeler, Harris, Burghen, & Moore, 1989;

La Greca et al., 1995); however, the roles of family members vary by age and developmental level of the youth. For example, caregivers often take primary responsibility for diabetes management tasks in childhood, but older children and adolescents tend to have increased responsibilities for management (Anderson et al., 1997; Ellis et al., 2007; La Greca, Follansbee, & Skyler, 1990). Developmental level is also important given that premature transfer of responsibility can lead to poor self-care and outcomes (Wyssocki et al., 1996). Ideally, the negotiation of a healthy sharing of responsibilities can be coordinated and sustained caregiver

involvement promoted. When caregivers remain involved, there are observed improvements in diabetes management and glycemic outcomes (Anderson et al., 1997; Ellis et al., 2007; Wiebe et al., 2005).

The Diabetes Family Responsibility Questionnaire (DFRQ) (Anderson, Auslander, Jung, Miller, & Santiago, 1990) was developed to examine how youth with type 1 diabetes and their caregivers share responsibilities around diabetes management. The DFRQ contains 17 items, and the youth and caregiver separately report who takes primary responsibility for that particular management task or if it is shared equally. The specific type of management task assumed by the different parties will affect diabetes care. It is possible that disagreement about who carries out a particular type of task may be more closely linked to glycemic control than other tasks. For example, prior research suggests that diabetes-specific family conflict around direct management tasks (e.g., taking insulin, monitoring blood glucose levels) is more closely linked with glycemic control than conflict around indirect management tasks (e.g., checking expiration dates on supplies, remembering clinic appointments) (Hood, Butler, Anderson, & Laffel, 2007). The DFRQ was submitted to factor analysis in the original study documenting its psychometric properties (Anderson et al., 1990) and resulted in a three-factor solution. Two of the factors, responsibilities related to diabetes regimen tasks and general health maintenance, appear to fall in to the category of direct management tasks. The third factor, social presentation of diabetes, includes tasks such as telling friends, school personnel, and relatives about diabetes; in other words, indirect management tasks. Thus, inspection of the DFRQ reveals that this measure contains both direct and indirect management tasks; however, associations between clusters of items, diabetes management, and glycemic control have not been examined.

Since the original factor analysis was conducted on the DFRQ in 1990, changes in caregiver involvement have occurred in caring for adolescents with type 1 diabetes. This includes new technology [e.g., continuous subcutaneous insulin infusion (CSII) therapy] allowing the adolescent greater independence in self-care. Additionally, the original factor analysis was only validated for the parent report measure in a sample of children under 12 years of age. Thus, validation of the factor structure of the DFRQ in adolescents older than 12 years and across both adolescent and caregiver reports of responsibility remains needed. The current study is the first to examine a two-factor structure of the DFRQ in an adolescent sample, across both parent and adolescent report. Given that separate factors (i.e., direct and indirect tasks) within the DFRQ might differentially

impact diabetes health outcomes, such investigation is needed; particularly in this high risk adolescent age group.

In this study, we examined cross-sectional associations between responsibility sharing, diabetes management, and glycemic control in adolescents with type 1 diabetes and their caregivers. We used responses on the DFRQ to conduct a factor analysis to clarify the distinction between direct and indirect management tasks. We then examined responsibility sharing with diabetes management (i.e., BGM frequency) and glycemic control (i.e., hemoglobin A1c value). We hypothesized that more caregiver responsibility would be associated with more frequent BGM and lower A1c values. We also hypothesized that direct management items would be more closely associated with BGM frequency and glycemic control than indirect management items.

## Research Design and Methods

### *Participants and Procedures*

A total of 261 adolescents (aged 13–18 years) with type 1 diabetes and their primary caregivers participated in a single assessment. All adolescents had a diagnosis of type 1 diabetes according to the practice guidelines of the American Diabetes Association (ADA) (Silverstein et al., 2005) and were receiving care from a multidisciplinary team at one of two pediatric diabetes centers (Northeastern and Midwestern clinical sites). Exclusion criteria included the presence of a major psychiatric or neurocognitive disorder that would inhibit ability to participate; a significant medical disease other than type 1 diabetes, treated thyroid disorders, or celiac disease; or the inability to read or understand English. At the Northeastern site, 126 adolescents participated. They were drawn from a sample of 173 eligible adolescents who were approached as a convenience sample about participation (agreement rate of 73%). At the Midwestern site, 150 adolescents participated from the 166 eligible adolescents similarly approached (agreement rate of 90%). We subsequently excluded all participants with diabetes duration under one year ( $n = 15$ ) because inspection of their data revealed significant variability in responsibility sharing during this first year of diabetes management. This left a final sample of 261 (Northeastern site,  $n = 121$ ; Midwestern site,  $n = 140$ ).

All study procedures were approved by the institutional review board at each clinical site. After obtaining written informed consent from caregivers and consent/assent from the adolescent, a research assistant administered questionnaires. All questionnaires were completed in the pediatric diabetes clinic before or after the adolescent's clinic visit.

## Measures

The 17-item Diabetes Family Responsibility Questionnaire (DFRQ) was used to assess sharing of responsibilities around diabetes management. This measure has strong psychometric properties (Anderson et al., 1990) and both caregivers and youth complete equivalent forms and assign one of the following values: 1 = adolescent taking or initiating responsibility for this task almost all the time; 2 = caregiver and adolescent sharing responsibility for this task almost equally; 3 = caregiver taking or initiating responsibility for this task almost all of the time. For adolescents, perceptions of parent responsibility in general, not specific to one parent, are assessed. Scores can range from 17 (adolescent has complete responsibility) to 51 (caregiver has complete responsibility). A score of 34 indicates equal sharing of responsibilities. In this sample, internal consistency was acceptable for both adolescents and caregivers (adolescent coefficient  $\alpha = .74$ ; caregiver coefficient  $\alpha = .77$ ).

At the time of the clinic appointment, participants' meters were downloaded (if available) (42.9% of adolescents did not bring a meter to download) and the daily frequency of BGM calculated across the past 14 days of data downloaded. The adolescent and caregiver also provided self-report of daily BGM frequency. In the absence of meter downloads, we adjusted the self-report value in the same manner as in prior work, by calculating an inflation ratio (the quotient of the meter report mean and the self-report mean) and multiplying the self-report data by this ratio (Herzer & Hood, 2010; McGrady, Laffel, Drotar, Repaske, & Hood, 2009). In our dataset, the inflation ratio was 0.97 due to a slight inflation in self-report for those 158 adolescents with both meter downloads and self-report. There were no differences between adolescents with and without meter download on any family or socio-demographic variables, A1c values, BGM frequencies, or caregiver or adolescent reports of responsibility sharing on the DFRQ ( $p > .05$ ).

Glycemic control (A1c) for the adolescents at the Northeastern site was calculated by high-performance liquid chromatography (reference range 4.0–6.0%, Tosoh 2.2; Foster City, CA). Adolescents at the Midwestern clinical site had their A1c values calculated by the DCA 2000+ (reference range 4.3–5.7%, Bayer Inc.; Tarrytown, NY). Prior studies have shown that A1c values obtained from the laboratory and DCA 2000+ measurements are highly correlated (Tamborlane et al., 2005).

Duration of diabetes and mode of insulin administration were obtained from chart review. Family demographic data were obtained from a self-report questionnaire

completed by the adolescent's primary caregiver during the study visit.

## Statistical Analyses

Prior to analysis, data were double entered and cross-checked for accuracy. Descriptive statistics, frequencies, and univariate comparisons were calculated for the total sample as well as for each site. Next, we ran a confirmatory factor analysis (CFA) with the 17 items of the DFRQ. This included setting the possible factors to two (direct and indirect management tasks) and conducting an orthogonal rotation (Varimax). Interpretation of the factor structure was based on the scree plot, eigenvalues, and the rotated factor pattern which produced standardized regression coefficients. Psychometric properties (e.g., internal consistency) and bivariate correlations between factors, BGM frequency, and A1c values were also calculated. Finally, separate multivariate analyses in the general linear model framework were conducted to determine the association between responsibility sharing, BGM frequency, and A1c values. Two models were run with BGM frequency as the dependent variable; one with the full DFRQ scales and one with the factor scores. Likewise, two models were run with A1c values as the dependent variable; BGM frequency was included as an independent variable in both of these models. We did this to test for significant differences between responsibility factor scores and the overall responsibility score on both BGM frequency and A1c. Covariates (adolescent age, gender, ethnicity, type 1 diabetes duration, and mode of insulin delivery; caregiver education level, insurance status, and marital status; clinical site) related to A1c and BGM frequency in previous literature (Lewin et al., 2006; Springer et al., 2006) were included in all models.

Analyses were conducted in SAS v9.1 (SAS Institute, Cary, NC).

## Results

### Participant Characteristics

Table 1 displays characteristics of the total sample of adolescents and caregivers as well as by clinical site. The mean age of the sample was  $15.7 \pm 1.4$  years with a duration of type 1 diabetes ranging from 1 to 16.8 years (mean duration =  $7.0 \pm 3.9$  years). The gender distribution was approximately equal, females (46%). The sample was largely white, not of Hispanic origin (87%). Seventy-eight percent of adolescents lived in two-caregiver families and 55% of caregivers had at least a college degree. The mean A1c for this sample was  $9.0 \pm 1.8\%$  with 56% on CSII. The mean A1c was similar to prior studies (Bryden, Peveler,

Table I. Participant Characteristics

	Total, <i>n</i> = 261	Northeast, <i>n</i> = 121	Midwest, <i>n</i> = 140
Age (years)*	15.7 ± 1.4	15.9 ± 1.4	15.5 ± 1.4
Gender (% female)	46.4%	42.2%	50.7%
Ethnicity (% white, not of Hispanic origin)	87.4%	89.3%	85.7%
Caregiver marital status (% married)	78.2%	82.6%	74.3%
Primary caregiver (% mother)	82.0%	77.7%	85.7%
Education level of primary caregiver (% with at least a college degree)*	54.8%	62.8%	47.9%
Insurance Status (% private)	83.9%	86.0%	82.1%
Type 1 diabetes duration (years)*	7.0 ± 3.9	7.6 ± 3.9	6.4 ± 3.8
Hemoglobin A1c (%)	9.0 ± 1.8	9.0 ± 1.6	8.9 ± 1.9
Blood glucose monitoring frequency (times daily)*	4.0 ± 1.8	4.3 ± 1.8	3.7 ± 1.7
Method of insulin delivery*			
Multiple daily injections (%)	44.1%	52.9%	36.4%
CSII (%)	55.9%	47.1%	63.6%
DFRQ Overall Score—Caregiver Report	33.2 ± 4.7	33.3 ± 5.0	33.1 ± 4.4
DFRQ Overall Score—Adolescent Report	29.8 ± 4.3	29.9 ± 4.3	29.6 ± 4.3

Note. Scores are shown as mean ± SD. CSII: Continuous subcutaneous insulin infusion. Significant differences between clinical sites (\**p* < .05).

Stein, Neil, Mayou, & Dunger, 2001; Horton, Berg, Butner, & Wiebe, 2009; Danne et al., 2001; Mortensen & Hougaard, 1997; Svoren, Volkening, Butler, Moreland, Anderson, & Laffel, 2007). Mean BGM frequency for this sample was 4.0 ± 1.8.

Analyses between the two clinical sites indicated that the participants at the Northeastern site were slightly older (*p* = .04), had a longer diabetes duration (*p* = .02), were more likely to use injections than CSII (*p* = .008), had a higher BGM frequency (*p* = .007) and had caregivers with higher educational attainment (*p* = .02). There were no significant differences on any other covariates or A1c levels. These observed differences between sites led us to include site as a covariate in the linear models.

### Descriptive Statistics and Univariate Associations

Based on the inspection of DFRQ score means, adolescents reported more responsibility (mean = 29.8 ± 4.3) while the caregivers endorsed more equal sharing of responsibilities (mean = 33.2 ± 4.7). Equal sharing of responsibility is indicated by a score of 34. Higher scores on the adolescent DFRQ (indicating more responsibility for the caregiver) were associated with younger age (*r* = -.36, *p* < .0001) and more frequent BGM (*r* = .15, *p* = .01). Higher scores on the caregiver DFRQ were associated with younger adolescent age (*r* = -.34, *p* < .0001) and higher A1c values (*r* = .15, *p* = .02). Adolescent and caregiver reports were correlated (*r* = .50, *p* < .0001). Of note, BGM frequency and A1c values were inversely correlated (*r* = -.50, *p* < .0001).

### CFA

The CFA for the adolescent DFRQ produced eigenvalues of 2.74 for the direct management factor and 0.94 for the indirect management factor. The two factors were correlated (*r* = .33) and a Varimax rotation produced the factor loadings displayed in Table II. The direct management factor included 11 items and included items such as “remembering to take insulin,” “remembering times when blood sugar should be monitored,” and “carrying sugar” for a hypoglycemic episode. The 11 direct management items had an internal consistency (coefficient alpha) of .73. The indirect management factor included six items, including “telling relatives about diabetes” and “making appointments” for healthcare visits. The six indirect management items had an internal consistency of 0.57. Only two items—remembering to rotate injection/infusion sites and remembering times to check blood glucose levels—were nearly equal in their loadings, but did load more so on the direct management factor.

The CFA for the caregiver DFRQ produced identical factors and associated items (see Table III). The eigenvalue for the direct management factor was 3.42 (11 items) and 0.82 for the indirect management factor (six items). These two factors were correlated (*r* = .35). After the Varimax rotation, the caregiver direct management factor included the same 11 items the adolescent report revealed as direct management tasks. The 11 direct management items on the caregiver DFRQ had an internal consistency of 0.80. The six indirect items had an internal consistency of 0.49 and included “remembering healthcare appointments” and “checking expiration dates on supplies.”

Table II. Results of the Adolescent DFRQ Factor Analysis

Item	Item content	Factor 1 Direct	Factor 2 Indirect
1	Remembering day of clinic appointment	-0.02	<b>0.43</b>
2	Telling teachers about diabetes	0.12	<b>0.43</b>
3	Remembering to take morning or evening injection or boluses (pump)	<b>0.53</b>	0.19
4	Making appointments with dentists and other doctors	-0.09	<b>0.42</b>
5	Telling relatives about diabetes	0.03	<b>0.31</b>
6	Taking more or less insulin according to results of blood sugar monitoring	<b>0.49</b>	0.31
7	Noticing differences in health, such as weight changes or signs of infection	<b>0.30</b>	0.18
8	Deciding what to eat at meals or snacks	<b>0.46</b>	-0.04
9	Telling friends about diabetes	<b>0.37</b>	0.02
10	Noticing the early signs of an insulin reaction	<b>0.36</b>	0.09
11	Giving injections or boluses (pump)	<b>0.54</b>	0.04
12	Deciding what should be eaten when family has meals out	<b>0.43</b>	-0.11
13	Carrying some form of sugar in case of an insulin reaction	<b>0.44</b>	0.11
14	Explaining absences from school to teachers or other school personnel	0.19	<b>0.37</b>
15	Rotating injection sites or infusion set-ups (pump)	<b>0.38</b>	0.28
16	Remembering times when blood sugar should be monitored	<b>0.43</b>	0.42
17	Checking expiration dates on medical supplies	0.21	<b>0.52</b>

Note: Values in bold typeface indicate onto which factor each item loaded.

Table III. Results of the Caregiver DFRQ Factor Analysis

Item	Item content	Factor 1 Direct	Factor 2 Indirect
1	Remembering day of clinic appointment	-0.06	<b>0.45</b>
2	Telling teachers about diabetes	0.26	<b>0.28</b>
3	Remembering to take morning or evening injection or boluses (pump)	<b>0.64</b>	0.26
4	Making appointments with dentists and other doctors	-0.12	<b>0.35</b>
5	Telling relatives about diabetes	0.09	<b>0.28</b>
6	Taking more or less insulin according to results of blood sugar monitoring	<b>0.60</b>	0.17
7	Noticing differences in health, such as weight changes or signs of infection	<b>0.37</b>	0.27
8	Deciding what to eat at meals or snacks	<b>0.56</b>	0.06
9	Telling friends about diabetes	<b>0.34</b>	-0.03
10	Noticing the early signs of an insulin reaction	<b>0.39</b>	-0.12
11	Giving injections or boluses (pump)	<b>0.62</b>	0.06
12	Deciding what should be eaten when family has meals out	<b>0.52</b>	0.01
13	Carrying some form of sugar in case of an insulin reaction	<b>0.38</b>	0.08
14	Explaining absences from school to teachers or other school personnel	0.27	<b>0.34</b>
15	Rotating injection sites or infusion set-ups (pump)	<b>0.52</b>	0.15
16	Remembering times when blood sugar should be monitored	<b>0.63</b>	0.17
17	Checking expiration dates on medical supplies	0.14	<b>0.50</b>

Note: Values in bold typeface indicate onto which factor each item loaded.

### Multivariate Analysis

General linear modeling was used to determine the correlates of BGM frequency and A1c with particular focus on the DFRQ total and factor scores (see Table IV).

#### Model 1: DFRQ Total Scores and BGM Frequency

The first model included the adolescent DFRQ total score, caregiver DFRQ total score, and covariates as independent variables; BGM frequency was the dependent variable.

The overall model was significant,  $F(11,249) = 7.14$ ,  $p < .0001$ ,  $R^2 = .24$ . Higher BGM frequency was associated with insulin delivery via CSII versus multiple daily injections (MDI) ( $p < .001$ ), higher caregiver education level ( $p = .003$ ), younger adolescent age ( $p < .001$ ), adolescents from the Northeastern versus Midwestern site ( $p < .001$ ), and adolescent DFRQ total score indicating higher levels of caregiver responsibility ( $p = .02$ ). Caregiver DFRQ total score was not significantly associated with BGM frequency.

Table IV. Results of General Linear Models

Model	Dependent variable	Variable	R <sup>2</sup>	F	β
1	BGM frequency		.24	7.14 <sup>†</sup>	
		Adolescent DFRQ total score			.07*
		Caregiver DFRQ total score			-.02
		Older age			-.28**
		Insulin delivery using injections vs. CSII			-.84**
		Lower caregiver education			-.65*
		Northeast site vs. Midwest site			.73**
		Longer type 1 diabetes duration			-.04
		Adolescent gender being male vs. female			-.02
		Caregiver marital status (single vs. married)			-.12
		Adolescent minority status (being a minority)			-.12
Adolescent has private insurance	.11				
2	BGM frequency		.24	6.14 <sup>†</sup>	
		Adolescent DFRQ—direct			.09*
		Adolescent DFRQ—indirect			.02
		Caregiver DFRQ—direct			-.01
		Caregiver DFRQ—indirect			-.06
		Older age			-.28**
		Insulin delivery using injections vs. CSII			-.87**
		Lower caregiver education			-.67*
		Northeast site vs. Midwest site			.68*
		Longer type 1 diabetes duration			-.04
		Adolescent gender being male vs. female			-.01
		Caregiver marital status (single vs. married)			-.14
		Adolescent minority status (being a minority)			-.14
		Adolescent has private insurance			.14
3	A1c		.28	8.05 <sup>†</sup>	
		Adolescent DFRQ total score			-.003
		Caregiver DFRQ total score			.03
		Older age			-.04
		Insulin delivery using injections vs. CSII			.47*
		Lower caregiver education			-.14
		Northeast site vs. Midwest site			.27
		Longer type 1 diabetes duration			.04
		Adolescent gender being male vs. female			.09
		Caregiver marital status (single vs. married)			.51
		Adolescent minority status (being a minority)			.38
		Adolescent has private insurance			-.33
		BGM Frequency			-.39 <sup>†</sup>
		4			A1c
Adolescent DFRQ—direct	.02				
Adolescent DFRQ—indirect	-.04				
Caregiver DFRQ—direct	.00				
Caregiver DFRQ—indirect	.10				
Older age	-.04				
Insulin delivery using injections vs. CSII	.46*				
Lower caregiver education	-.14				
Northeast site vs. Midwest site	.28				
Longer type 1 diabetes duration	.04				
Adolescent gender being male vs. female	.09				
Caregiver marital status (single vs. married)	.52*				
Adolescent minority status (being a minority)	.40				
Adolescent has private insurance	-.33				
BGM frequency	-.39 <sup>†</sup>				

Note. \*p < .05; \*\*p < .001; †p < .0001.

### Model 2: DFRQ Factor Scores and BGM Frequency

The second model substituted DFRQ factor scores (both adolescent and caregiver) for the total scores used in Model 1. The overall model was significant,  $F(13,247) = 6.14$ ,  $p < .0001$ ,  $R^2 = .24$ . Higher BGM frequency was significantly associated with the same covariates (insulin delivery method, adolescent age, site, and caregiver education) as well as the adolescent report of higher levels of caregiver responsibility on direct management tasks ( $p = .02$ ). Adolescent report of responsibility sharing on indirect management tasks and both caregiver DFRQ factors scores were not significantly associated with BGM frequency.

### Model 3: DFRQ Total Score and A1c

The third model was similar to Model 1 except that A1c was the dependent variable and BGM frequency was included as an independent variable. This model was significant,  $F(12,248) = 8.05$ ,  $p < .0001$ ,  $R^2 = .28$ . Higher A1c values were associated with lower BGM frequency ( $p < .0001$ ) and mode of insulin delivery via MDI versus CSII ( $p = .04$ ). Adolescent and caregiver reports of responsibility sharing (total DFRQ scores) were not significantly associated with A1c.

### Model 4: DFRQ Factor Scores and A1c

The fourth model used the DFRQ factor scores instead of the total scores; A1c was the dependent variable. The overall model was significant,  $F(14,246) = 7.00$ ,  $p < .0001$ ,  $R^2 = .28$ . Higher A1c was significantly associated with lower BGM frequency ( $p < .0001$ ), mode of insulin delivery via MDI versus CSII ( $p = .05$ ), and single caregiver marital status ( $p = .05$ ). Adolescent and caregiver DFRQ factor scores were not significantly associated with A1c.

## Discussion

This study demonstrates two main conclusions regarding the associations between responsibility sharing, diabetes management, and glycemic control in adolescents with type 1 diabetes assessed cross-sectionally. First, adolescent perception of responsibility sharing, particularly when characterized by greater caregiver responsibility, is critical to better diabetes management. Second, adolescents' perception of greater caregiver responsibility around direct management tasks is more salient to BGM frequency than responsibility around indirect management tasks. These findings suggest that attempts to improve diabetes management (e.g., increase BGM frequency) in this age group may be most effective not only when the caregiver

is more involved, but also when the adolescent in particular *perceives* greater caregiver responsibility.

In a recent multi-site study, dyadic agreement on responsibility sharing was significantly correlated with A1c in youth younger than age 12 ( $M = 10.6$  years old), but not in older youth ( $M = 13.5$  years old) (Anderson et al., 2009). Our findings are similar and highlight that in this age group, adolescent perception of greater caregiver responsibility is particularly important around direct management tasks for BGM frequency; although it was not associated with diabetes control. The peripheral tasks such as making appointments or telling school personnel about diabetes have nonsignificant associations with diabetes management and control, possibly because these indirect tasks are largely being carried out by caregivers. Data from this study support this notion. Examining long-term associations between responsibility sharing and BGM frequency (i.e., adherence) and their association with diabetes control may help to better understand these relationships.

The results specific to the factor structure and psychometric properties of the DFRQ advance our understanding of this construct in adolescents with type 1 diabetes. Specifically, the original validation study for the DFRQ (Anderson et al., 1990) did not reveal a meaningful factor structure for the child/adolescent report, even after splitting in to age groups (i.e., above and below age 12). While the original three-factor structure of the caregiver DFRQ had more robust eigenvalues (5.10, 1.85, and 1.54) than our two-factor solution (3.42 and 0.82), the two-factor solution fit both the adolescent and caregiver reports of the DFRQ. This suggests that in adolescents with type 1 diabetes and their families, responsibility sharing can be viewed as relating to either direct or indirect management tasks. This may provide more specific targets for clinic-based interventions (e.g., increase responsibility sharing around several direct tasks) toward the end of improving overall diabetes management.

We found other important covariates that affect diabetes management and control that are worth mentioning. Higher BGM frequency was associated with younger adolescent age, higher levels of caregiver education, and insulin delivery via CSII instead of MDI. Our results are consistent with previous work (Harris et al., 2000; Johnson, Silverstein, Rosenbloom, Carter, & Cunningham, 1986) that illustrates that as children age into adolescence, there is a decline in adherence, inclusive of BGM frequency. Additionally, lower levels of education were associated with lower BGM frequency and caregivers who were not married had adolescents with higher A1c values; both associations may be explained through socioeconomic status (SES). Previous studies indicate that low

SES families tend to exhibit poorer diabetes management and control, likely due to competing needs and limited resources (Harris, Greco, Wysocki, Elder-Danda, & White, 1999; Overstreet, Holmes, Dunlap, & Frentz, 1997). The association between insulin delivery via CSII and higher BGM frequency is likely related to both situations where adolescents who are on CSII tend to check blood glucose levels more frequently as well as clinic standards of adherence prior to initiating CSII. In either case, higher BGM frequency is associated with CSII use. Similar to past findings, BGM frequency was tightly associated with better A1c values (Gavin & Wysocki, 2006; Johnson et al., 1992; Laffel et al., 2006). While there is no direct association between greater caregiver responsibility and A1c in this age group, the promotion of BGM frequency and other indicators of better diabetes management may promote more optimal glycemic outcomes.

This study has limitations. First, this study employs a cross-sectional design. Longitudinal research on responsibility sharing among adolescent-caregiver dyads may help to elucidate the directional effect of responsibility sharing on diabetes management, as well as its link with glycemic control. Second, we relied on self-report measures for responsibility sharing and have no objective measure of this construct. While we found that adolescent perception of caregiver responsibility was an important correlate of diabetes management, it is possible that this perception differs from what actually goes on in the daily management of type 1 diabetes. Consequently, depending on who is more accurate (adolescents or caregivers), interventions may need to be altered (e.g., family problem solving intervention if adolescents are correctly perceiving less caregiver responsibility). Third, pubertal status was not measured in this study. While the current sample included only youth aged 13 and above who were most likely post-pubertal, previous research (Moreland et al., 2004) has suggested important relationships between pubertal status and glycemic control that should be further explored. Fourth, there was a discrepancy between sites as to the method of obtaining A1c values (HPLC at the Northeastern site versus DCA 2000+ at the Midwestern site). In order to minimize the statistical impact of this limitation, we controlled for site in the preliminary analyses and in our final linear models. Fifth, the indirect factors in our CFA, by both adolescent and caregiver report, had eigenvalues less than 1.0 (.94, .82 respectively). However, this factor accounted for 24.9% of the variance (total variance = 97.4%) by adolescent report and 17.5% of the variance (total variance = 89.9%) by caregiver report, suggesting that both factors are needed to more accurately assess the underlying

construct assessed (i.e., responsibility). Furthermore, the indirect factors had lower reliability. The indirect factors included a broader range of tasks which may account for the lower reliability of the factors and may have led to our inability to find significance within the models for indirect management. Lastly, although the sociodemographic characteristics of our study sample are representative of the larger population of youth with type 1 diabetes (Mortensen & Hougaard, 1997; Springer et al., 2006; Svoren et al., 2007), future studies utilizing more diverse samples by over-sampling may provide different findings.

In sum, data from this study suggest that for adolescents with type 1 diabetes to achieve success in the management of their diabetes as they gain greater autonomy in their self-care, the adolescents must perceive caregiver responsibility in the management of their diabetes. This requires that responsibility sharing of caregivers is explicit and clearly identified by the adolescent. Explicit responsibility sharing appears to be particularly important for direct management tasks such as monitoring blood glucose levels, changing or rotating sites for insulin delivery, and responding to blood glucose levels. Thus, clinic-based and clinical research interventions for adolescents must include explicit caregiver responsibility sharing that is acknowledged by the adolescents in order to promote better diabetes management and glycemic control for adolescents with type 1 diabetes.

## Funding

National Institutes of Health (K23 DK073340 to K.K.H.).

*Conflicts of interest:* None declared.

## References

- Anderson, B., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology, 15*(4), 477–492.
- Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics, 130*(2), 257–265.
- Anderson, B., Holmbeck, G., Iannotti, R. J., McCay, S. V., Lochrie, A. S., Volkening, L. A., et al. (2009). Dyadic measures of the parent-child relationship during the transition to adolescence and glycemic control in



- children with type 1 diabetes. *Families, Systems & Health*, 27(2), 141–152.
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care*, 24(9), 1536–1540.
- Danne, T., Mortensen, H. B., Hougaard, P., Lynggaard, H., Aanstoot, H. J., Chiarelli, F., . . . Aman, J. (2001). Persistent differences among centers over 3 years in glycemic control and hypoglycemia in a study of 3,805 children and adolescents with type 1 diabetes from the Hvidore Study Group. *Diabetes Care*, 24(8), 1342–1347.
- Ellis, D. A., Podolski, C. L., Frey, M., Naar-King, S., Wang, B., & Moltz, K. (2007). The role of parental monitoring in adolescent health outcomes: impact on regimen adherence in youth with type 1 diabetes. *Journal of Pediatric Psychology*, 32(8), 907–917.
- Gavin, L., & Wysocki, T. (2006). Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness. *Journal of Pediatric Psychology*, 31(5), 481–489.
- Hanson, C. L., Henggeler, S. W., Harris, M. A., Burghen, G. A., & Moore, M. (1989). Family system variables and the health status of adolescents with insulin-dependent diabetes mellitus. *Health Psychology*, 8(2), 239–253.
- Harris, M. A., Greco, P., Wysocki, T., Elder-Danda, C., & White, N. H. (1999). Adolescents with diabetes from single-parent, blended, and intact families: Health-related and family functioning. *Families, Systems & Health*, 17, 181–196.
- Harris, M. A., Wysocki, T., Sadler, M., Wilkinson, K., Harvey, L. M., Buckloh, L. M., . . . White, N. H. (2000). Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care*, 23, 1301–1304.
- Herzer, M., & Hood, K. K. (2010). Anxiety symptoms in adolescents with type 1 diabetes: Association with blood glucose monitoring and glycemic control. *Journal of Pediatric Psychology*, 35(4), 415–425.
- Hood, K. K., Butler, D. A., Anderson, B. J., & Laffel, L. M. (2007). Updated and revised Diabetes Family Conflict Scale. *Diabetes Care*, 30(7), 1764–1769.
- Horton, D., Berg, C. A., Butner, J., & Wiebe, D. J. (2009). The role of parental monitoring in metabolic control: Effect on adherence and externalizing behaviors during adolescence. *Journal of Pediatric Psychology*, 34(9), 1008–1018.
- Johnson, S. B., Kelly, M., Henretta, J. C., Cunningham, W., Tomer, A., & Silverstein, J. (1992). A longitudinal analysis of adherence and health status in childhood diabetes. *Journal of Pediatric Psychology*, 17, 537–553.
- Johnson, S. B., Silverstein, J., Rosenbloom, A., Carter, R., & Cunningham, W. (1986). Assessing daily management in childhood diabetes. *Health Psychology*, 5(6), 545–564.
- La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B. Jr., & Santiago, J. V. (1995). I get by with a little help from my family and friends: adolescents' support for diabetes care. *Journal of Pediatric Psychology*, 20(4), 449–476.
- La Greca, A. M., Follansbee, D. M., & Skyler, J. S. (1990). Developmental and behavioral aspects of diabetes management in youngsters. *Children's Health Care*, 19, 132–139.
- Laffel, L. M., Volkening, L. A., Hood, K. K., Lochrie, A. S., Nansel, T. R., Anderson, B. J., & Weissberg-Benchell, J. (2006). Optimizing Glycemic Control in Youth with T1DM: Importance of BG Monitoring and Supportive Family Communication. *Diabetes*, 55(6), [Abstract].
- Lewin, A. B., Heidgerken, A. D., Geffken, G. R., Williams, L. B., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Pediatric Psychology*, 31(2), 174–183.
- McGrady, M. E., Laffel, L., Drotar, D., Repaske, D., & Hood, K. K. (2009). Depressive symptoms and glycemic control in adolescents with type 1 diabetes: Mediation role of blood glucose monitoring. *Diabetes Care*, 32(5), 804–806.
- Moreland, E. C., Tovar, A., Zuehlke, J. B., Butler, D. A., Milaszewski, K., & Laffel, L. M. (2004). The impact of physiological, therapeutic and psychosocial variables on glycemic control in youth with type 1 diabetes mellitus. *Journal of Pediatric Endocrinology & Metabolism*, 17(11), 1533–1544.
- Mortensen, H.B., & Hougaard, P. (1997). Comparison of metabolic control in a cross-sectional study of 2,873 children and adolescents with IDDM from 18 countries. The Hvidore Study group on childhood diabetes. *Diabetes Care*, 20(5), 714–720.
- Overstreet, S., Holmes, C. S., Dunlap, W. P., & Frenz, J. (1997). Sociodemographic risk factors to disease control in children with diabetes. *Diabetes Medicine*, 14(2), 153–157.
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., . . . Clark, N.

- (2005). Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care*, 28(1), 186–212.
- Springer, D., Dziura, J., Tamborlane, W. V., Steffen, A. T., Ahern, J. H., Vincent, M., & Weinzimer, S. A. (2006). Optimal control of type 1 diabetes mellitus in youth receiving intensive treatment. *The Journal of Pediatrics*, 227–232.
- Svoren, B. M., Volkening, L. K., Butler, D. A., Moreland, E. C., Anderson, B. J., & Laffel, L. M. (2007). Temporal trends in the treatment of pediatric type 1 diabetes and impact on acute outcomes. *Journal of Pediatrics*, 150(3), 279–285.
- Tamborlane, W. V., Kollman, C., Steffes, M. W., Ruedy, K. J., Dongyuan, X., . . . Beck, R. W. (2005). Comparison of fingerstick hemoglobin A1c levels assayed by DCA 2000 with the DCCT/EDIC central laboratory assay: results of a Diabetes Research in Children Network (DirecNet) Study. *Pediatric Diabetes*, 6(1), 13–16.
- Wiebe, D. J., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., . . . Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology*, 30(2), 167–178.
- Wysocki, T., Taylor, A., Housh, B. S., Linscheid, T. R., Yeates, K. O., & Naglieri, J. A. (1996). Deviation from developmentally appropriate self-care autonomy. Association with diabetes outcomes. *Diabetes Care*, 19, 119–125.