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## Coping and resilience in adolescents with type 1 diabetes

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## Abstract

**Background**—Adolescents with type 1 diabetes (T1D) must cope with the ongoing stress of treatment management, so it is important to identify the most adaptive coping strategies. Previous studies, however, have typically measured broad categories of coping (e.g. approach/avoidance) and few used instruments specifically designed for this population.

**Objective**—This article aimed to use a developmentally sensitive coping measure to explore how the use of specific coping strategies impacts resilience (i.e. quality of life, competence and metabolic control) in adolescents with T1D.

**Methods**—Thirty adolescents with T1D between the ages of 10 and 16 and their mothers completed questionnaires on adolescents' coping strategy use, competence and quality of life. Clinical data (i.e. HbA1c) were obtained from adolescents' medical records.

**Results**—Greater use of primary control coping strategies (e.g. problem solving, emotional expression) was associated with higher competence scores, better quality of life and better metabolic control. Secondary control coping strategies (e.g. acceptance, distraction) were related to higher social competence, better quality of life and better metabolic control. Finally, the use of disengagement coping strategies (e.g. withdrawal or denial) was linked with lower competence and poorer metabolic control.

**Conclusions**—The results of this study support the use of developmentally sensitive coping measures by researchers and clinicians to determine the most effective coping strategies for adolescents with T1D.

## Keywords

adolescent development; diabetes mellitus; resilience; type 1

## Introduction

Type 1 diabetes (T1D) is a chronic medical condition that affects over 176 000 American children and adolescents. The peak age of onset is puberty, which makes adolescence an important developmental period to study within the context of this condition (Liese 2006). A diagnosis is often a source of significant stress due to the demands of treatment management, as well as the need to incorporate a pre-existing self-concept with the reality that one is now an individual living with a chronic illness (Grey & Thurber 1991; Davidson *et al.* 2004). Adolescents must also navigate these uncertain waters during a developmental stage hallmarked by hormonal fluctuations and physical changes (ADA 2009). To help

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manage this stress, adolescents with T1D frequently rely on one or more coping strategies (Graue *et al.* 2004).

#### **Coping measures**

Lazarus and Folkman (1984) were the first researchers to extensively study coping, defining it as 'constantly changing cognitive and behavioral efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the resources of the person' (p. 141). Their model divided coping strategies into two main categories: problem-focused and emotion-focused coping strategies (Lazarus & Folkman 1984). Subsequent researchers adopted a similar two-pronged structure in their models but used different terms, such as approach/avoidance, to define similar concepts (e.g. Reid et al. 1994). These coping models have frequently been used to identify connections between coping and adjustment in a variety of populations, including adolescents with T1D. In general, studies suggest that avoidant (or emotion-focused) coping strategies are related to poorer psychosocial outcomes, poorer treatment adherence and poorer metabolic control, but approach (or problem-focused) coping strategies are related to fewer depressive symptoms and better metabolic control in youth with T1D (Delamater et al. 1987; Grey et al. 1991; Reid et al. 1994, 1995; Graue et al. 2004). More recently, however, researchers have noted that these broad categories of coping are neither exclusive nor exhaustive (Skinner et al. 2003). For example, a coping strategy such as forming a plan may help to solve a problem and also help to relieve negative emotions. Likewise, social support seeking does not easily fit within either category. Thus, there is a need to build on previous coping research in youth with T1D by using measures that reflect newer conceptualizations of coping.

It is also important to consider developmental stage when assessing coping strategies in adolescents. Compas and colleagues (2001) recognize the role of development in coping, noting that responses to stress 'both draw on and are constrained by the biological, cognitive, social and emotional development of the individual' (p.89). Their empirically validated model separates voluntary coping strategies into primary control engagement coping strategies, secondary control engagement coping strategies and disengagement coping strategies. Primary control engagement coping strategies are defined as coping attempts directed towards influencing objective events or conditions (e.g. problem solving) or directly regulating one's emotions (e.g. emotional expression). Secondary control engagement coping strategies are defined as efforts to fit with or adapt to the environment (e.g. acceptance or cognitive restructuring). Finally, disengagement coping strategies are defined as responses that are oriented away from the stressor or one's responses to it (e.g. withdrawal or denial) (Connor-Smith et al. 2000). This model has been used successfully to measure coping in paediatric populations of children and adolescents, but it has not yet been tested in youth with T1D (Compas et al. 2006; Schreier & Chen 2008; Campbell et al. 2009).

#### Resilience

Increasingly, researchers have focused on factors that promote successful adaptation to T1D (e.g. good quality of life, better metabolic control). These positive outcomes in the context of a potentially adverse environment may be considered indicators of resilience (Luthar *et al.* 2000; Masten 2007). Previous research indicates that higher levels of resilience correlate with higher levels of self-esteem and hope among children with chronic illnesses (Grey *et al.* 1998), and in adolescents with T1D, better quality of life has been linked to fewer depressive symptoms, less stress related to coping with diabetes and less family conflict around diabetes management (Grey *et al.* 1998; Laffel *et al.* 2003). Another indicator of resilience is competence (Garmezy *et al.* 1984). In youth with T1D, social competence has been associated with better emotional well-being, better ability to manage stress, and better

metabolic control (Hanson *et al.* 1987; Daviss *et al.* 1995; La Greca *et al.* 1995). However, youth with T1D have been found to have lower levels of perceived competence than youth with acute illness (Jacobson *et al.* 1997). While family cohesion and social support have been shown to have a positive impact on resilience (Amer 1999), there is still a need to examine resilience in relation to coping in this population, using developmentally appropriate models.

#### The current study

The current study used Compas and colleagues' model of coping to examine the association between the use of specific types of coping strategies and indicators of resilience (i.e. competence, quality of life and metabolic control) in adolescents with T1D. First, we described the extent to which adolescents used primary engagement, secondary engagement and/or disengagement coping strategies to deal with diabetes-related stress. Then we identified links between specific coping strategies and indicators of resilience (i.e. competence, quality of life and metabolic control). Based on previous research, we expected that greater use of primary and secondary engagement coping strategies and lower use of disengagement coping strategies would be associated with higher levels of resilience in adolescents with T1D.

## Methods

#### Sample and setting

The study included 30 adolescents and their mothers from a university diabetes clinic (see Table 1 for demographics). Participants were between the ages of 10 and 16 [using Lerner and Steinberg's (2004) definition of adolescence as the 'second decade of life'], had no other major health issues, were able to speak and read English, and had been diagnosed for at least 6 months.

#### Instruments

Methods of coping—The Responses to Stress Questionnaire (RSQ, Connor-Smith et al. 2000) assessed coping strategies used by adolescents in response to diabetes-related stressors. The first 10 questions were designed to be developmentally specific to the concerns of adolescents with T1D (e.g. feeling different from one's peers, parental nagging about diabetes care) (Davidson *et al.* 2004), measured on a 4-point Likert scale (0 = never, 1) = a few times, 2 = many times and 3 = every day). These first 10 items were summed to yield a total stressor score, with a possible total of 30 (higher scores indicate higher levels of perceived stress). The following 57 items assessed adolescents' responses to the stressors identified in the first 10 questions. The RSQ is designed to evaluate all responses to stress; however, the current analyses focus on the three voluntary coping factors: primary control engagement coping (9 items: problem solving, emotional modulation, emotional expression), secondary control engagement coping (12 items: positive thinking, cognitive restructuring, acceptance, distraction) and disengagement coping (9 items: avoidance, denial, wishful thinking). Previous studies using the RSQ have demonstrated that the questionnaire has good reliability, validity and internal consistency (Connor-Smith et al. 2000; Compas *et al.* 2006). In our sample, internal consistency was as follows:  $\alpha = 0.75$  for primary control coping,  $\alpha = 0.71$  for secondary control coping and  $\alpha = 0.70$  for disengagement coping. To account for individual differences in overall levels of coping strategies used, ratio scores were determined by dividing the number of primary, secondary and disengagement coping strategies by the total number of coping strategies used by each adolescent (Connor-Smith et al. 2000).

**Child competence**—The Child Behavior Checklist was completed by mothers to assess their children's competence over the past 6 months (CBCL, Achenbach & Rescorla 2001). The Youth Self Report was completed by the adolescents and assessed their perception of their own competence (YSR, Achenbach & Rescorla 2001). The CBCL and YSR were both normed on a large national sample and provide age- and gender-based *t* scores. (Achenbach & Rescorla 2001). For the current study, the Social Competence and Total Competence scales were used as the best indicators of resilience. Poorer competence is reflected in lower scores on the competence scales.

**Quality of life**—Quality of life was measured using the Pediatric Quality of Life questionnaire (PedsQL, Varni *et al.* 1999). In the current study, we used the core measure, designed to measure quality of life in youth with chronic health conditions (23 items), and the diabetes-specific scale that specifically addresses quality of life related to diabetes symptoms (11 items). Higher scores indicate a higher degree of quality of life. Internal consistency was as follows for the current sample: Total Score  $\alpha = 0.84$ , Diabetes scale  $\alpha = 0.75$ .

**Metabolic control**—Glycosylated haemoglobin (HbA1c) was obtained from adolescents' medical record as an objective measure of metabolic control over the past 8–12 weeks. An HbA1c of <8% is considered acceptable control for school-age children and adolescents (ADA 2009). Analyses were performed using the Bayer Diagnostics DCA2000<sup>®</sup> machine, which provides results on a finger-stick blood sample (normal range = 4.2–6.3%).

#### Procedures

Eligible adolescents were recruited from the university diabetes clinic during their regularly scheduled clinic visits. Of the 85 families approached, 82% expressed interest, but 57% were unable to be contacted or scheduled (as this was a pilot study, there were limited time and resources to follow up with families). There were no significant differences in race/ ethnicity, maternal education, or marital status between families who participated and those who did not. In line with the university Institutional Review Board requirements, the principal investigator or a research assistant read and explained the consent/assent forms. Once consent/assent was obtained, questionnaires were completed in a quiet, private room. Adolescents and their mothers also participated in a videotaped discussion of diabetes stress; these results are presented elsewhere (Jaser & Grey 2010). Adolescents and their mothers were compensated for their time (\$20 each).

## Results

#### Preliminary analyses

Analyses were performed using SPSS (v. 16.0, Chicago, IL) statistical packages. Preliminary analyses were conducted to determine whether there were significant effects for age or gender on the key variables. The only significant gender difference was for primary control coping; girls reported using primary control coping strategies more than boys (girls' mean ratio score = 0.22, boys' mean ratio score = 0.19, F = 10.29, P = 0.003).

#### Descriptive statistics for stress and coping

Table 2 indicates the descriptive statistics for each variable. In general, adolescents reported moderate levels of diabetes-related stress; scores ranged from 4 to 17, with a mean of 10.47 (SD = 3.43). Adolescents reported using secondary control coping strategies most often, accounting for 20–36% of their total stress response (mean ratio score for secondary control coping =0.28, SD = 0.04). The use of primary control coping strategies accounted for 13–28% of their total stress response (mean ratio score for primary control coping =0.20, SD =

0.03), and the use of disengagement coping strategies accounted for 11-25% of their total stress response (mean ratio score for disengagement coping =0.17, SD = 0.04).

#### **Correlational analyses**

Bivariate correlations (Pearson's *r*) were conducted to test the association among primary engagement, secondary engagement, and disengagement coping strategies, respectively, and competence (CBCL and YSR), quality of life (PedsQL), and metabolic control (HbA1c). Table 2 indicates that higher levels of diabetes-related stress were associated with significantly lower use of primary control (r = -0.48) and secondary control coping strategies (r = -0.36), but stress was not related to disengagement coping. Greater use of primary control coping was related to significantly higher parent- and self-reported social competence (r = 0.38, 0.39 respectively) and higher parent-reported total competence (r = 0.35). Use of primary control coping strategies was also associated with better diabetes-related quality of life (r = 0.40) as well as better total quality of life (r = 0.48). Finally, greater use of primary control was related to better metabolic control (r = -0.42, all P < 0.05).

Greater use of secondary control coping strategies was related to higher parent-reported social competence (r = 0.37), and somewhat higher parent-reported total competence (r = 0.36, P = 0.072). However, the use of secondary control coping strategies was not related to self-reported competence. Greater use of secondary control coping strategies was also related to better total quality of life (r = 0.54), but was not associated with diabetes-related quality of life. Finally, greater use of secondary control coping was related to better metabolic control in adolescents (r = -0.43).

Greater use of disengagement coping strategies was related to lower self-reported social competence (r = -0.45). However, disengagement coping strategies were not significantly related to total competence or parent-reported social competence. Disengagement coping strategies were not significantly associated with diabetes-related quality of life or total quality of life. Finally, greater use of disengagement coping was associated with poorer metabolic control (r = 0.40).

#### Group differences in competence

Finally, to determine whether there was a difference in coping strategies used by adolescents with lower resilience scores, we created comparison groups using the clinical cut-off scores on the CBCL and YSR for Total Competence (*t* score  $\leq 40 =$  borderline clinical, <16th percentile). Twenty per cent (*n* = 6) of adolescents' self-reported total competence was in the borderline-clinical or clinical range on the YSR (*t* score  $\leq 40$ ), indicating that they perceived themselves as having lower competence than 84% of the national normative sample. Maternal reports indicated that 18% (*n* = 5) of mothers rated their adolescent children in the borderline-clinical or clinical range for total competence. We then conducted analyses of variance to compare groups (average competence and low competence) according to each of the three coping factors.

There was a significant difference between self-reported average and low competence groups on disengagement coping [F(1,29) = 12.22, P = 0.002], such that the low competence groups used more disengagement coping (mean = 0.21), as compared with the average competence groups (mean = 0.16). Differences in use of primary control coping strategies between groups approached significance [F(1,29) = 3.65, P = 0.07], with higher levels in the average competence group. There were no significant differences in coping strategies between parent-reported competence groups (CBCL competence).

## Discussion

The current study is one of the first to examine coping in relation to resilience in adolescents with T1D. The results of this study using a developmentally sensitive measure of coping indicated that adolescents were most likely to use secondary control coping strategies, followed by primary control coping and disengagement coping strategies to deal with diabetes-related stress. Greater use of primary control coping strategies, such as problem solving and emotional expression, was associated with several positive outcomes indicative of resilience, including higher competence levels, higher quality of life and better metabolic control. Similarly, greater use of secondary control coping strategies, such as acceptance and distraction, was associated with higher quality of life and better metabolic control. As adolescents' perceived stress increased, however, they were less likely to use these adaptive strategies. Finally, disengagement coping strategies, such as avoidance and denial, were associated with lower levels of resilience, as evidenced by lower levels of competence and poorer metabolic control.

Similar to other studies (e.g. Band & Weisz 1990; Reid et al. 1994; Graue et al. 2004), adolescents in our sample who used primary control coping strategies to manage diabetesrelated stress enjoyed higher social competence (per both parent and self-report) and better quality of life, suggesting that the use of such strategies may promote resilience. These results are perhaps unsurprising, given that youth who use strategies such as problem solving are more likely to be perceived by others as more competent. The lack of a significant association between secondary control coping and self-reported competence in our sample suggests that secondary coping strategies may have a more subtle effect on an adolescent's overall well-being - one that may be less noticeable, yet still valuable. Secondary control coping strategies, such as cognitive restructuring, may be effective in helping adolescents deal with chronic diabetes-related stressors that cannot be directly addressed, such as feeling different from peers (e.g. Edgar & Skinner 2003). It is important to note that greater use of secondary control coping strategies was related to better metabolic control, similar to studies in other paediatric populations reporting associations between the use of secondary control coping strategies and positive health outcomes, such as better asthma control and less pain (Compas et al. 2006; Schreier & Chen 2008).

The use of disengagement coping strategies in our sample was associated with some negative outcomes – including poorer metabolic control – and no positive outcomes. This conclusion is supported by previous literature, which has demonstrated associations between similar coping strategies (e.g. emotion-focused coping strategies such as mental and behavioral disengagement, avoidance, and wishful thinking) and negative outcomes, including lower quality of life and poorer metabolic control (Delamater *et al.* 1987; Grey *et al.* 1997; Graue *et al.* 2004). It is likely that the use of strategies such as withdrawal or denial could result in problems with parents and peers, and therefore poorer quality of life and social competence. These findings must be interpreted with caution, however, because of the small number of youth in the low competence group (n = 6).

The findings regarding social competence have important implications for adolescents with T1D. Adolescence is a developmental stage characterized by wanting to fit in with one's peers; therefore, fears of non-acceptance may cause adolescents to be reluctant to disclose their diagnosis or to deliberately skip self-management tasks in the presence of peers (e.g. blood glucose monitoring, insulin injections or boluses) (Davidson *et al.* 2004). Although studies suggest that peers provide an important source of emotional support for adolescents with T1D (La Greca *et al.* 1995), many adolescents express apprehension about the reactions of peers to their diabetes self-management tasks (Hains *et al.* 2006). Social competence has been identified as an area of particular vulnerability for adolescents with T1D (Jacobson *et al.* 2004).

*al.* 1997) and the current study provides some of the first evidence of coping strategies that may promote social competence in this population.

#### Limitations

There are a few important limitations to this study. First, fathers were not included in the analysis, and recent studies suggest that fathers play an important role in diabetes management (e.g. Wysocki & Gavin 2006). However, the literature also suggests that mothers tend to be the parent primarily responsible for treatment, which is why they were the focus of this study (Kovacs *et al.* 1990). Another limitation is the inability to assess causal factors, due to the study's cross-sectional design. We cannot know from these data whether coping leads to resilience, or whether more resilient youth are more likely to use adaptive coping strategies. Future longitudinal studies are needed to explore these relationships. Finally, the study is limited both by the small sample size and the demographics and treatment practices of the clinic (e.g. percentage of youth on insulin pump therapy may differ across clinics).

#### **Conclusions/implications**

The current study provides clinicians and researchers with specific data on coping strategy use among adolescents with T1D by using detailed, developmentally appropriate methods. The fact that primary control and secondary control coping strategies were associated with positive outcomes, including better metabolic control, suggests that there may be value in educating patients about these coping strategies. Likewise, given the significant negative outcomes associated with the use of disengagement coping strategies, including poorer metabolic control, clinicians might consider discouraging the use of such strategies. Talking with adolescents about ways they may incorporate adaptive coping strategies into their lives, using relevant examples, may increase the likelihood that they will use them (Sanz 2003).

The small sample size of this study necessarily limits the impact of its findings; however, the methodology and results have the potential to guide future studies. Results from the current study may provide estimates of effect sizes to test these relationships in larger, longitudinal studies. If these results are replicated, clinicians could use the findings to inform coping strategy education tools and training modules, and to teach patients about the types of coping strategies they can use to improve their health outcomes, promote competence and increase quality of life.

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#### Key messages

- Adolescents with T1D experience ongoing stress related to treatment management.
- Developmentally sensitive, detailed measures of coping are needed for adolescents with T1D.
- Study results suggest that adaptive coping in adolescents with T1D is related to resilience.

## Table 1

## Demographic characteristics (n = 30)

Variable	Range	Mean ± SD or %
Child age	10–16 years	$12.6\pm1.6$
Child gender	Female	52%
	Male	48%
Race/ethnicity	White	74%
	Black	13%
	Hispanic	13%
Duration of diabetes	7-249 months	$69.1\pm56.2$
Treatment type	Insulin pump	74%
	Multiple injections	26%
HbA1c	5.5-13.4	$7.9 \pm 1.5$
Maternal age	30-57 years	$43.47\pm6.7$
Maternal education	Less than high school	7%
	High school/GED	16%
	Associates/some college	17%
	College degree	32%
	Graduate degree	29%
Annual family income	<\$40 000/year	17%
	\$40 000-\$80 000/year	34%
	>\$80 000/year	48%

Table 2

Descriptive statistics and correlations

	1	2	3	4	5	6	7	8	6	10	
1. Total stress $M = 10.47$ (3.43)	I										
2. Primary $M = 0.20 (0.03)$	-0.48	I									
3. Secondary $M = 0.27 (0.04)$	-0.36	0.47**	I								
4. Disengagement $M = 0.17 (0.04)$	0.24	-0.50**	-0.19	I							
5. YSR social comp. M = 10.07 (2.25)	-0.10	$0.39^*$	0.17	-0.48	I						
6. YSR total comp. $M = 23.28 (4.38)$	-0.11	$0.54^{**}$	0.26	-0.54 **	$0.88^{***}$	I					
7. CBCL social comp. M = 9.17 (2.53)	-0.12	0.38*	0.37*	-0.30	0.72***	$0.64^{***}$	I				
8. CBCL total comp. M = 25.78 (4.56)	-0.02	0.35	0.36	-0.22	0.69***	0.69***	0.88***	I			
9. PedsQL total $M = 86.71 (8.85)$	-0.37	$0.48^{**}$	$0.54^{**}$	-0.01	0.15	0.20	0.20	0.32	I		
10. PedsQL diabetes $M = 71.39 (12.37)$	-0.31	0.32	0.26	-0.12	0.21	0.22	0.07	0.19	$0.64^{***}$	I	
11. HbA1C M = 7.87 (1.47)	0.24	-0.42	-0.43	$0.40^*$	-0.22	-0.33	-0.24	-0.26	-0.20	-0.05	
Values in parentheses are	standard dev	iations.									
$^{*}_{P < 0.05}$ ,											

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 ${}^{**}_{P < 0.01}$ ,

\*\*\* P < 0.001.

CBCL, Child Behavior Checklist; PedsQL, Pediatric Quality of Life; YSR, Youth Self Report.