



# Illness Identity in Adolescents and Emerging Adults With Type 1 Diabetes: Introducing the Illness Identity Questionnaire

*Diabetes Care* 2016;39:757–763 | DOI: 10.2337/dc15-2559

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## OBJECTIVE

The current study examined the utility of a new self-report questionnaire, the Illness Identity Questionnaire (IIQ), which assesses the concept of illness identity, or the degree to which type 1 diabetes is integrated into one's identity. Four illness identity dimensions (engulfment, rejection, acceptance, and enrichment) were validated in adolescents and emerging adults with type 1 diabetes. Associations with psychological and diabetes-specific functioning were assessed.

## RESEARCH DESIGN AND METHODS

A sample of 575 adolescents and emerging adults (14–25 years of age) with type 1 diabetes completed questionnaires on illness identity, psychological functioning, diabetes-related problems, and treatment adherence. Physicians were contacted to collect HbA<sub>1c</sub> values from patients' medical records. Confirmatory factor analysis (CFA) was conducted to validate the IIQ. Path analysis with structural equation modeling was used to examine associations between illness identity and psychological and diabetes-specific functioning.

## RESULTS

CFA indicated that the IIQ has a clear factor structure, meaningfully differentiating four illness identity dimensions. Rejection was related to worse treatment adherence and higher HbA<sub>1c</sub> values. Engulfment was related to less adaptive psychological functioning and more diabetes-related problems. Acceptance was related to more adaptive psychological functioning, fewer diabetes-related problems, and better treatment adherence. Enrichment was related to more adaptive psychological functioning.

## CONCLUSIONS

The present findings underscore the importance of the concept of illness identity. A valid and reliable measure, the IIQ, is introduced to measure four illness identity dimensions in individuals with type 1 diabetes. These four illness identity dimensions were uniquely related to psychological and diabetes-specific functioning.

Adolescence and emerging adulthood are important developmental periods to establish lifelong routines of diabetes care in individuals with type 1 diabetes (1). To achieve optimal diabetes care routines, adolescents and emerging adults need to incorporate type 1 diabetes management as part of their daily life and, consequently, need to integrate diabetes into their sense of self or identity (2). Identity development constitutes a core developmental task during adolescence (3) that

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Received 26 November 2015 and accepted 20 February 2016.

This article contains Supplementary Data online at <http://care.diabetesjournals.org/lookup/suppl/doi:10.2337/dc15-2559/-/DC1>.

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may well extend into the late teens and twenties (a period known as emerging adulthood), due to the postponement of adult role attainment in current postmodern societies (4). Emerging adulthood is a time of possibilities and explorations in domains such as work and love and, hence, constitutes a time of opportunities for most individuals (4). However, emerging adulthood is also characterized by increased instability and insecurity, which may be experienced as stressful by some individuals (4). Those with a chronic illness, such as type 1 diabetes, may experience additional challenges such as assuming more responsibility for diabetes management (5). Hence, integrating diabetes into one's sense of self may be an important task during this period (6). Although most individuals succeed in managing the developmental and diabetes-related challenges, a subgroup of adolescents and emerging adults with type 1 diabetes shows increased risk for poor glycemic control, difficulties in diabetes care, and difficulties in daily functioning (7).

To understand why certain individuals experience such difficulties, whereas others succeed in managing these challenges, the current study forwards the concept of illness identity or the degree to which diabetes becomes integrated into one's personal sense of self (L.O., J.R., S.P., M.V., L.G., P.M., C.A.B., I.W., K.L., unpublished data). In an attempt to bridge different psychological, sociological, and health perspectives on illness and self-related variables, the current study introduces a newly developed questionnaire, the Illness Identity Questionnaire (IIQ) (L.O., J.R., S.P., M.V., L.G., P.M., C.A.B., I.W., K.L., unpublished data), which focuses on four different illness identity dimensions: rejection, engulfment, acceptance, and enrichment.

Constructing such a new questionnaire was deemed necessary for three reasons. First, to our knowledge, no existing questionnaire explicitly focuses on the concept of rejection, possibly because it has been mainly studied in qualitative research (8). Second, existing questionnaires assess only a limited number of illness identity dimensions, such as the Illness Self-Concept Scale (ISCS), which is designed to measure illness self-concept centrality, an engulfment-like state (9). Third, some measures include items seemingly tapping into different

illness identity dimensions but were not designed specifically to distinguish among these dimensions. The ISCS, for instance, seems to include items tapping into an engulfment-like state (e.g., "my illness dictates nearly everything I do") as well as into an acceptance-like state (e.g., "I have preserved my sense of self, in spite of my illness"), but the latter items need to be reverse scored and added to the engulfment items. Hence, when being analyzed in such a way, the ISCS does not allow for examining the potential distinctiveness of different illness identity dimensions.

The first two identity dimensions, engulfment and rejection, capture a lack of illness integration, or the degree to which having diabetes is not well integrated as part of one's sense of self. Engulfment refers to the degree to which diabetes dominates a person's identity. Individuals completely define themselves in terms of their diabetes, which invades all domains of life (9). Rejection refers to the degree to which diabetes is rejected as part of one's identity and is viewed as a threat or as unacceptable to the self. Hence, having diabetes is not integrated in one's sense of self. Consequently, these individuals may neglect the self-management behaviors necessitated by their diabetes, potentially leading to suboptimal treatment adherence (8).

In contrast to these two illness identity dimensions, two other dimensions capture more adaptive illness integration: acceptance and enrichment. Acceptance refers to the degree to which individuals accept diabetes as a part of their identity, besides other social roles and identity assets. These individuals do not feel overwhelmed by their diabetes (9,10) and try to lead as normal a life as possible, without neglecting the self-management behaviors (11). Enrichment refers to the degree to which having diabetes results in positive life changes, benefits one's identity, and enables one to grow as a person (12). Positive changes as a result of different stressors, also referred to as posttraumatic growth, have been documented in adolescence (13). These changes can manifest themselves in different ways, including an increased appreciation for life, a change of life priorities, and a more positive view of the self (14).

Previous quantitative research assessing similar constructs has suggested that the

degree to which individuals integrate their illness into their identity may affect psychological and diabetes-specific functioning in patients. Diabetes intruding upon all domains of life (similar to engulfment) was related to more depressive symptoms and more diabetes-related problems (6). In contrast, acceptance has been related to fewer depressive symptoms and diabetes-related problems and to better glycemic control (6,15). Similarly, benefit finding has been related to fewer depressive symptoms and better treatment adherence (16).

The current study introduces the IIQ in individuals with type 1 diabetes as a way to assess all four illness identity dimensions. Three main study objectives were addressed: 1) to assess the factorial validity and reliability of the IIQ in a large sample of adolescents and emerging adults with type 1 diabetes; 2) to explore associations with demographic (sex and age) and clinical parameters (illness duration and insulin administration); and 3) to investigate unique associations of the four illness identity dimensions with psychological (depressive symptoms and quality of life) and diabetes-specific functioning (diabetes-related problems, treatment adherence, and glycemic control; i.e., criterion validity).

## RESEARCH DESIGN AND METHODS

### Participants and Procedure

Patients were selected from the Belgian Diabetes Register using the following criteria: diagnosis of type 1 diabetes, between 14 and 25 years old, and Dutch speaking. Patients with impaired cognitive abilities (as reported by their parents) were excluded. A total of 1,450 patients were contacted; 53 unopened questionnaire packages were returned because of an unknown or wrong address. A total of 575 patients (46.1% male) returned completed questionnaires, which equals a response rate of 41.16%. All patients signed an informed consent form. Parental informed consent was asked for minors, and questionnaires from four minors were excluded because parental informed consent was lacking. All patients received a small reward (a movie ticket) for participation.

### Measures

#### *Illness Identity*

The IIQ is a newly developed measure tapping into four illness identity dimensions

(L.O., J.R., S.P., M.V., L.G., P.M., C.A.B., I.W., K.L., unpublished data) and was used for the first time in patients with type 1 diabetes. The item pool included items from existing measures focusing on constructs related to illness identity (e.g., refs. 9,10) as well as newly generated items, semantically based on these measures. Patients were asked to indicate how much they agreed with each statement on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). All items can be found in Table 2.

#### Depressive Symptoms

Depressive symptoms were measured by the 20-item Center for Epidemiologic Studies Depression Scale (CESD) (17). The CESD was developed for adults (aged 18 and older) but has also been validated in adolescents and emerging adults (18). Each item asks how often participants had experienced depressive symptoms during the past week, using a 4-point scale from 0 (seldom) to 3 (most of the time or always). Four item scores have to be reversed before the total score (ranging from 0 to 60) is computed. A sample item is, "I felt that everything I did was an effort." Higher scores indicate more depressive symptoms. A total of 25.7% scored 16 or higher. This cutoff of 16 does not necessarily suggest a clinical diagnosis but suggests the presence of psychological disturbance (17). The Cronbach  $\alpha$  was 0.91.

#### Satisfaction With Life

The Satisfaction With Life Scale (SWLS) (19–21) was used, consisting of five items on a 5-point Likert response scale, ranging from 1 (disagree strongly) to 5 (agree strongly). The SWLS was developed for adults (aged 18 and older) but has also been validated in adolescents (20) and emerging adults (21). A sample item is, "I am satisfied with my life." Higher scores indicate higher satisfaction with life. The Cronbach  $\alpha$  was 0.85.

#### Treatment Adherence

The Self-Care Inventory (SCI) (22), a 14-item self-report measure, was used. The SCI was developed for adults (aged 18 and older) but has also been validated in adolescents (23). The SCI includes items that focus on blood glucose testing and monitoring, insulin and food regulation, exercise, and emergency precautions. Item 12, "Wearing a medic alert ID," was deleted because this is not always part of treatment in Belgium. The SCI was translated

in Dutch using the back-translation procedure (24). For each item, individuals were requested to indicate how well they followed their prescribed regimen for diabetes care in the past month on a 5-point scale, ranging from 1 (never do it) to 5 (always do this as recommended without fail), or they could indicate that the item was not applicable. A mean adherence score was calculated. Higher scores indicate better treatment adherence. The Cronbach  $\alpha$  was 0.77.

#### Diabetes-Related Problems

Illness adaptation was assessed by the Problem Areas in Diabetes Scale (PAID) (25), which was developed for adults (aged 18 and older) and has also been used in emerging adults specifically (6). It measures diabetes-related emotional, food, treatment, and social support problems. Sample items are, "Feeling discouraged with your diabetes regimen (treatment; 3 items)," "Feelings of deprivation regarding food and meals" (food; 3 items), "Feeling alone with diabetes" (social support; 2 items), and "Feeling scared when you think about living with diabetes" and "Feeling constantly burned out by the constant effort to manage diabetes" (emotional; 12 items). The total score was calculated as the average of the four problem areas. Higher scores indicate more diabetes-related problems. The Cronbach  $\alpha$  was 0.94.

#### Glycemic Control

HbA<sub>1c</sub> values that were closest to the date the patients filled out the questionnaires (i.e., in a window of 3 months before and after questionnaire completion) were collected from patients' medical records by contacting the treating physicians. HbA<sub>1c</sub> values were converted from Diabetes Control and Complications Trial (DCCT)-derived units (as %) to International Federation of Clinical Chemistry and Laboratory Medicine–recommended units (as mmol/mol). HbA<sub>1c</sub> values below 7.0% or 53 mmol/mol are recommended; higher HbA<sub>1c</sub> values indicate poorer glycemic control (26).

#### Statistical Analyses

Analyses were conducted in three steps, according to the three main objectives. First, to evaluate the model fit of the hypothesized four-factor solution of the IIQ (i.e., factorial validity), we conducted confirmatory factor analysis (CFA) using Mplus 7.31. To deal with nonnormal data distributions, maximum likelihood

mean variance was used as a robust estimation method (27). To evaluate model fit, we used the  $\chi^2$  index, which should be as small as possible; the root mean square error of approximation (RMSEA), which should be less than 0.08; the comparative fit index (CFI), which should exceed 0.90; and the standardized root mean square residual (SRMR), which should be less than 0.09 (28). Second, MANOVA, using Wilks  $\Lambda$ , was used to test for mean differences based on sex and insulin administration type (injections vs. pump) for all study variables. A univariate ANOVA was conducted for HbA<sub>1c</sub> values. For age and illness duration, Pearson correlation coefficients were calculated with all study variables. Third, path analysis with structural equation modeling was used to examine the unique associations linking illness identity to psychological and diabetes-specific functioning (i.e., criterion validity). In addition, to examine the unique effects of illness identity, both path models were controlled for sex, age, illness duration, and insulin administration by estimating covariances with all study variables.

## RESULTS

### Participants' Characteristics

Table 1 represents participants' characteristics for the total sample and the subgroup for which HbA<sub>1c</sub> values were obtained. HbA<sub>1c</sub> values (mean 61 mmol/mol, SD 15.6; 7.75%, SD 1.43) were obtained for 431 patients (47.1% males) who did not differ in sex ( $df = 1$ ;  $\chi^2 = 0.65$ ,  $P = 0.42$ ), but differed in mean age ( $F_{1,564} = 26.491$ ,  $P < 0.001$ ,  $\eta^2 = 0.05$ ) and illness duration ( $F_{1,564} = 28.591$ ,  $P < 0.001$ ,  $\eta^2 = 0.05$ ) from the remaining 140 participants. Participants with HbA<sub>1c</sub> were younger (mean 18.48 years; SD 3.36) and had a shorter illness duration (mean 6.99 years; SD 4.84) than other participants (mean 20.09 years, SD 2.59; and mean 9.53 years, SD 4.90, respectively). The analyses including HbA<sub>1c</sub> were conducted on these 431 patients.

### Objective 1: Factorial Validity and Reliability of IIQ

#### CFA

CFA indicated that the hypothesized four-factor model (including two error correlations between related items within a single latent factor) had an adequate fit ( $df = 316$ ;  $\chi^2 = 659.583$ ,  $P < 0.001$ ; RMSEA = 0.047; CFI = 0.915; SRMR = 0.063). Table 2 presents all

**Table 1—Participants' characteristics**

	All participants (n = 571)	Participants with HbA <sub>1c</sub> (n = 431)
HbA <sub>1c</sub> (%) <sup>a</sup>	—	7.8 (1.4)
HbA <sub>1c</sub> (mmol/mol) <sup>a</sup>		61 (15.6)
Sex (%)		
Men	46.1	47.1
Women	53.9	52.9
Age (years) <sup>a</sup>	18.9 (3.3)	18.5 (3.4)
Age at diagnosis (years) <sup>a</sup>	11.0 (5.5)	11.5 (5.7)
Illness duration (years) <sup>a</sup>	7.6 (5.0)	7.0 (4.8)
Insulin administration (%)		
Injection	79.0	80.8
Pump	21.0	19.2
Civil status (more than 1 option) (%)		
Living with parents	72.0	75.6
Living with partner/(re)married	7.4	6.3
Relationship (living separately)	23.5	16.7
Single	12	11.7
Work (%)		
Student	75.5	78.0
Working	19.7	17.7
Unemployed	3.7	3.0
Education (%)		
University or college	21.3	19.8
General secondary education	33.5	33.7
Technical or vocational education	36.3	36
Primary education	6.1	7.5
Unqualified	2.7	3.1

<sup>a</sup>Data are shown as mean (SD).

standardized factor loadings for the four-factor solution. The 25th, 50th, and 75th percentiles were, respectively, 1.50, 2.13, and 2.67 for engulfment; 1.40, 2.00, and 3.00 for rejection; 3.33, 4.00, and 4.67 for acceptance; and 2.25, 2.88, and 3.63 for enrichment.

#### Correlations and Reliability of the IIQ

The Cronbach  $\alpha$  was 0.90 for engulfment, 0.84 for rejection, 0.85 for acceptance, and 0.90 for enrichment. Acceptance correlated positively with enrichment ( $r = 0.38$ ,  $P < 0.001$ ) but negatively with rejection ( $r = -0.64$ ,  $P < 0.001$ ) and engulfment ( $r = -0.56$ ,  $P < 0.001$ ). Engulfment correlated positively with rejection ( $r = 0.50$ ,  $P < 0.001$ ) but negatively with enrichment ( $r = -0.10$ ,  $P < 0.012$ ). Rejection correlated negatively with enrichment ( $r = -0.33$ ,  $P < 0.001$ ).

#### Objective 2: Associations With Demographic and Clinical Parameters

First, we tested for mean sex differences and found significant multivariate effects for illness identity ( $F_{1,563} = 0.97$ ,  $P = 0.004$ ,  $\eta^2 = 0.01$ ), psychological functioning ( $F_{1,561} = 0.96$ ,  $P < 0.001$ ,  $\eta^2 = 0.04$ ), and diabetes-specific functioning ( $F_{1,541} = 0.98$ ,

$P = 0.005$ ,  $\eta^2 = 0.02$ ). No mean sex differences were found for HbA<sub>1c</sub> values ( $F_{1,427} = 0.02$ ,  $P = 0.903$ ,  $\eta^2 = 0.00$ ). As reported in Table 3, men scored higher on acceptance and satisfaction with life and lower on engulfment, depressive symptoms, and diabetes-related problems than women.

Second, we tested for mean differences based on insulin administration type and found significant multivariate effects for illness identity ( $F_{1,561} = 3.72$ ,  $P = 0.005$ ,  $\eta^2 = 0.03$ ), but not for psychological functioning ( $F_{1,559} = 1.21$ ,  $P = 0.300$ ,  $\eta^2 = 0.00$ ), diabetes-specific functioning ( $F_{1,540} = 0.80$ ,  $P = 0.448$ ,  $\eta^2 = 0.00$ ), and HbA<sub>1c</sub> values ( $F_{1,425} = 1.84$ ,  $P = 0.175$ ,  $\eta^2 = 0.00$ ). As reported in Table 3, patients administering injections scored lower on engulfment than patients using a pump.

Third, age and illness duration were uncorrelated with illness identity and psychological functioning but were negatively correlated with treatment adherence (respectively,  $r = -0.20$ ,  $P < 0.001$  and  $r = -0.11$ ,  $P = 0.011$ ). Illness duration was also positively correlated with HbA<sub>1c</sub> values ( $r = 0.11$ ,  $P = 0.023$ ).

#### Objective 3: Criterion Validity: Unique Associations With Psychological Functioning and Diabetes-Specific Functioning

The initial path model including the four illness identity dimensions, diabetes-related problems, treatment adherence, depressive symptoms, and satisfaction with life, did not provide an adequate fit to the data across all indices ( $df = 5$ ;  $\chi^2 = 24.469$ ,  $P < 0.001$ ; RMSEA = 0.085; CFI = 0.987; SRMR = 0.024). After excluding all nonsignificant associations with the control variables (sex, age, illness duration, and insulin administration), the model was more parsimonious and provided an adequate fit ( $df = 23$ ;  $\chi^2 = 31.742$ ,  $P = 0.106$ ; RMSEA = 0.027; CFI = 0.994; SRMR = 0.024). All significant path coefficients are displayed in Fig. 1. Engulfment was positively related to depressive symptoms and diabetes-related problems but negatively to satisfaction with life. Rejection was negatively related to treatment adherence. Acceptance was negatively related to depressive symptoms and diabetes-related problems, but positively to satisfaction with life and treatment adherence. Finally, enrichment was positively related to satisfaction with life.

With respect to the path model including HbA<sub>1c</sub> values, an adequate fit across all indices was obtained ( $df = 5$ ;  $\chi^2 = 9.72$ ,  $P = 0.084$ ; RMSEA = 0.047; CFI = 0.991; SRMR = 0.021). Again for reasons of parsimony, all nonsignificant associations with the control variables were trimmed ( $df = 8$ ;  $\chi^2 = 7.174$ ,  $P = 0.5180$ ; RMSEA = 0.000; CFI = 1.000; SRMR = 0.024). Rejection was positively related to HbA<sub>1c</sub> values ( $\beta = 0.14$ ,  $P = 0.039$ ).

#### CONCLUSIONS

Illness identity has been forwarded as a key construct toward diabetes-related functioning in various research literature. In the current study, a new self-report questionnaire, the IIQ, measuring four illness identity dimensions (engulfment, rejection, acceptance, and enrichment), was validated in patients with type 1 diabetes. As an indication of criterion validity, these illness identity dimensions were found to be uniquely related to psychological and diabetes-specific functioning. Consequently, the concept of illness identity may help to clarify why certain adolescents and emerging adults with diabetes show difficulties in daily functioning, whereas others succeed in

**Table 2—Factor loadings of the IIQ**

Item	Factor loading
<b>Engulfment items</b>	
16. My diabetes completely consumes me.	0.82
15. My diabetes influences all my thoughts and feelings.	0.78
17. It seems as if everything I do is influenced by my diabetes.	0.77
13. My diabetes has a strong impact on how I see myself.	0.74
12. My diabetes dominates my life.	0.72
19. My diabetes limits me in many things that are important to me.	0.69
14. I am preoccupied with my diabetes.	0.64
18. My diabetes prevents me from doing what I would really like to do.	0.60
<b>Rejection items</b>	
5. I just avoid thinking about my diabetes.	0.80
2. I'd rather not think of my diabetes.	0.77
1. I refuse to see my diabetes as part of myself.	0.74
4. I hate being talked to about my diabetes.	0.69
3. I never talk to others about my diabetes.	0.58
<b>Acceptance items</b>	
9. I am able to place my diabetes in my life.	0.87
8. I accept being a person with diabetes.	0.85
11. I have learned to accept the limitations imposed by my diabetes.	0.79
7. My diabetes is part of who I am.	0.56
6. My diabetes simply belongs to me as a person.	0.55
10. I have a clear picture or understanding of my diabetes.	0.49
<b>Enrichment items</b>	
22. Because of my diabetes, I have become a stronger person.	0.79
23. Because of my diabetes, I realize what is really important in life.	0.77
26. Because of my diabetes, I have learned to work through problems and not just give up.	0.75
20. Because of my diabetes, I have grown as a person.	0.71
27. Because of my diabetes, I have learned to enjoy the moment more.	0.71
24. Because of my diabetes, I have learned a lot about myself.	0.70
21. Because of my diabetes, I know what I want out of life.	0.70
25. My diabetes has brought me closer to my friends and family.	0.59

For CFA, all factor loadings are significant at  $P < 0.001$ . For the official version of the questionnaire, please contact the first author.

managing developmental and diabetes-specific challenges.

### Objective 1: Factorial Validity and Reliability

Psychometric analysis of the IIQ, based on CFA, correlations, and the Cronbach  $\alpha$ , demonstrated that the four illness identity dimensions could be clearly differentiated and that all four subscales of the IIQ were reliable. Hence, these four subscales seem to measure different but interrelated dimensions. Engulfment and rejection were positively associated because they both capture a lack of illness integration. Acceptance and enrichment were positively interrelated because they both capture instances of having integrated diabetes into one's sense of self. Further, they were both negatively related to engulfment and rejection. As such, these findings demonstrate the utility of differentiating among these four illness identity dimensions in patients with type 1 diabetes. The associations

obtained with the various study variables further testify to the clinical value of distinguishing among these different dimensions. In sum, the IIQ was demonstrated to be a valid and reliable measure of the four illness identity dimensions.

### Objective 2: Associations With Demographic and Clinical Parameters

First, men scored higher on acceptance but lower on engulfment compared with women. Generally, women (both adolescents and adults) indeed experience greater health concerns and a greater tendency to adopt the sick role than men (29,30), which might give rise to feelings of engulfment. Furthermore, male emerging and young adults (18–35 years old) typically use more active coping and less avoidant coping to deal with their diabetes, which might enable them to better integrate diabetes into their identity (15,31).

Second, in line with previous studies (15), age and illness duration were

unrelated to illness identity, suggesting that being older or having a longer illness duration in itself does not inhibit or facilitate the integration of diabetes in one's identity. Apparently, all four illness identities can occur at any time during one's illness trajectory. For instance, whereas some individuals may experience engulfment at the initial stages of their illness, others may still feel engulfed after having the illness for more than a decade. Hence, it might be important for practitioners to realize that although patients might have lived with diabetes for a long time, they still might experience difficulties in integrating diabetes into their identity.

Finally, patients using an insulin pump scored higher on engulfment than patients administering injections. Although having a pump can increase flexibility in one's eating schedule and decrease fear for hypoglycemia, it can also make patients feel different and less accepted in terms of body image and social appearance (32). In addition, the pump is sometimes experienced as a constant reminder of diabetes and a burden during daily activities (33), which might explain the heightened engulfment in patients using a pump.

### Objective 3: Criterion Validity: Unique Associations With Psychological Functioning and Diabetes-Specific Functioning

The four illness identity dimensions all showed unique relationships with psychological and diabetes-specific functioning. First, in line with previous research that has focused on diabetes intruding into all domains of life, engulfment was related to more depressive symptoms, more diabetes-related problems (6), and lower satisfaction with life. When diabetes dominates a person's identity and daily life, it may interfere with other identity-related issues (e.g., romantic relationships and educational exploration) for young persons, which has been associated with worse psychological and diabetes-specific functioning (34).

Second, rejection (i.e., individuals ignoring diabetes as part of their identity) was negatively related to treatment adherence and glycemic control (8,35). As such, rejection may be a way for patients to avoid being overwhelmed by their diabetes and to limit its emotional effect (35) by avoiding confrontation with, for



**Table 3—Univariate ANOVAs, means, and *F* values for sex and insulin administration type**

Variables	Total	Sex		<i>F</i> value ( $\eta^2$ )	Insulin administration type		<i>F</i> value ( $\eta^2$ )
		Men	Women		Injection	Pump	
<b>Illness identity</b>							
Engulfment	2.19 (0.88)	2.08 (0.87)	2.28 (0.87)	7.20** (0.01)	2.15 (0.86)	2.38 (0.91)	6.40* (0.01)
Rejection	2.25 (1.00)	2.21 (1.00)	2.29 (1.00)	1.02 (0.00)	2.28 (1.01)	2.18 (0.96)	0.90 (0.00)
Acceptance	3.91 (0.86)	4.03 (0.84)	3.81 (0.87)	9.46** (0.02)	3.92 (0.86)	3.84 (0.90)	0.83 (0.00)
Enrichment	2.90 (0.94)	2.88 (0.95)	2.93 (0.84)	0.36 (0.00)	2.92 (0.95)	2.86 (0.91)	0.30 (0.00)
<b>Psychological functioning</b>							
Depressive symptoms	11.77 (10.63)	9.55 (10.00)	13.66 (10.79)	21.76*** (0.04)	11.46 (10.46)	12.95 (10.97)	1.84 (0.00)
Satisfaction with life	5.02 (1.16)	5.19 (1.15)	4.88 (1.14)	10.63** (0.02)	5.06 (1.15)	4.88 (1.17)	2.16 (0.00)
<b>Diabetes-specific functioning</b>							
Diabetes problems	1.02 (0.80)	0.90 (0.80)	1.12 (0.80)	10.66** (0.02)	1.02 (0.81)	1.02 (0.77)	0.00 (0.00)
Treatment adherence	3.73 (0.55)	3.77 (0.53)	3.70 (0.56)	2.02 (0.00)	3.74 (0.57)	3.67 (0.94)	1.33 (0.00)
HbA <sub>1c</sub> (mmol/mol)	61 (15.6)	61 (16.7)	61 (14.5)	0.02 (0.00)	61 (16.4)	63 (11.8)	1.84 (0.00)

SDs are given within parentheses. HbA<sub>1c</sub> values are reported in International Federation of Clinical Chemistry and Laboratory Medicine—recommended units as mmol/mol. \**P* < 0.05. \*\**P* < 0.01. \*\*\**P* < 0.001.

example, high blood glucose levels. However, as the present findings clearly demonstrate, rejecting diabetes as part of one's sense of self may reduce motivation to adhere to treatment regimens, leading to worse treatment adherence and, consequently, glycemic control (36).

Third, in line with previous research, acceptance (i.e., diabetes being integrated in one's identity) was related to fewer depressive symptoms and diabetes-related problems and to better satisfaction with life and treatment adherence (6,29). Hence, the present findings testify to the importance of integrating diabetes in one's identity because acceptance was strongly related

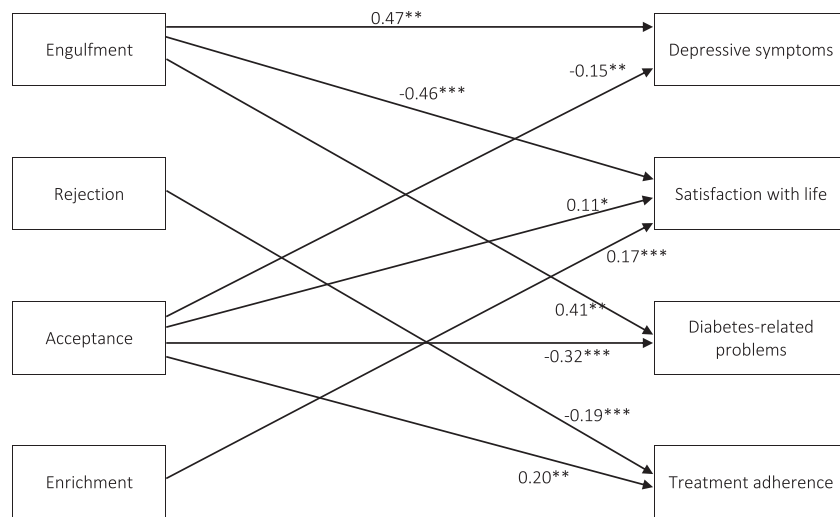
to adaptive psychological and diabetes-specific functioning, even when other illness identity dimensions were taken into account. When young persons are able to accept diabetes as part of their identity, they might be better equipped to cope with diabetes-specific challenges and manage their diabetes in the transition to adulthood (15,36).

Finally, enrichment (i.e., experiencing self-growth because of diabetes) was related to better satisfaction with life but was unrelated to depressive symptoms. Although previous research was characterized by some mixed findings, a meta-analysis has indeed demonstrated that stress-related positive changes were

more strongly related to positive psychological outcomes than to negative ones such as depressive symptoms (13). Experiencing positive life changes and personal growth as a result of diabetes might be a way for patients to cope with diabetes-related stress, thereby increasing satisfaction with life (16).

### Clinical Implications

The current study can have important implications for diabetes care. Identifying the degree to which individuals integrate diabetes into their identity seems important during adolescence and emerging adulthood in order to optimize psychological and diabetes-specific functioning. When individuals reject their diabetes or feel engulfed by their diabetes, they may not be motivated to adhere to their treatment. Motivation could be increased through challenging rejection and engulfment and inducing acceptance, or potentially, enrichment. Individuals indeed seem to benefit when they are able to accept their illness as part of their identity without the illness dominating their lives. The multidisciplinary clinical team supporting the patient can play an important role in this challenging task, for example, by challenging negative thoughts about diabetes or reducing avoidance behavior (37). To increase our understanding of how illness identity comes into place and develops over time, future research should also investigate potential determinants of the four illness identity dimensions to inform clinical interventions aimed at stimulating illness integration.



**Figure 1**—Final path model linking illness identity to outcome measures. Associations with sex, age, illness duration, and insulin administration type; associations among the different illness identity dimensions; and associations among satisfaction with life, depressive symptoms, diabetes-related problems, and treatment adherence are not shown for reasons of clarity. All coefficients are standardized. \**P* < 0.05. \*\**P* < 0.01. \*\*\**P* < 0.001.

## Limitations and Suggestions for

### Future Research

First, all measures, except for HbA<sub>1c</sub> values, were self-report questionnaires. Although self-report questionnaires are the most appropriate method to gather information regarding internal processes, such as illness identity, other methods (e.g., interviews) should be used in future research. This would allow for a more in-depth understanding of illness identity. Second, this cross-sectional study could not establish directionality of effects between illness identity and psychological and diabetes-specific functioning. Future longitudinal research needs to investigate the directionality of effects and how illness identity emerges and develops through adolescence and emerging adulthood. Finally, despite the large sample of participants ( $n = 575$ ), the relatively low response rate (41.16%) might reduce the generalizability of our findings.

### Conclusion

The IIQ is a valid and reliable new instrument to capture four different ways of integrating diabetes into one's identity. Our findings provided evidence for the hypothesis that engulfment and rejection capture rather maladaptive illness identity dimensions, whereas acceptance and enrichment are more adaptive ways of illness integration, each with their own unique correlates. Acceptance and engulfment were most strongly related to psychological and diabetes-specific functioning. Hence, adequately integrating diabetes into one's identity seems an important developmental task for adolescents and emerging adults to achieve adaptive psychological and diabetes-specific functioning.

**Acknowledgments.** The authors thank Chris Groven and the staff of the Belgian Diabetes Register for their help in collecting the data.

**Funding.** Funding was provided by FWO Flanders through research project G.0B35.14N to K.L.

**Duality of Interest.** No potential conflicts of interest relevant to this article were reported.

**Author Contributions.** L.O. researched data and wrote the manuscript. J.R., S.P., M.V., L.G., P.M., C.A.B., and I.W. contributed to the discussion and reviewed and edited the manuscript. K.L. helped to research the data, contributed to the discussion, and reviewed and edited the manuscript. L.O. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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