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Illness identity and adjusting to type 1 diabetes:

A four-wave longitudinal study

Jessica Rassart, PhD^{1,2}

Leen Oris, PhD^{1,2}

Sofie Prikken, MSc^{1,2}

Eveline R. Goethals, PhD^{1,3}

Koen Raymaekers, MSc^{1,2}

Ilse Weets, PhD⁴

Philip Moons, PhD^{1,5,6}

Koen Luyckx, PhD^{1,7}

¹KU Leuven, Leuven, Belgium; ²Research Foundation – Flanders, Belgium; ³Joslin Diabetes Center, Harvard Medical School, Boston, Massachusetts, USA; ⁴UZ Brussel University Hospital– Brussels, Belgium; ⁵University of Gothenburg, Gothenburg, Sweden; ⁶University of Cape Town, South Africa; ⁷UNIBS, University of the Free State, Bloemfontein, South Africa

Correspondence should be sent to Jessica Rassart, KU Leuven, Faculty of Psychology and Educational Sciences, Tiensestraat 102 (box 3717), 3000 Leuven, Belgium. Tel: 32 (0)16 373092. Fax: 32 (0)16 326144. E-mail: Jessica.Rassart@kuleuven.be.

Abstract

Objectives. Prior research has linked illness identity – or the extent to which the illness is integrated into one’s identity – to diabetes-specific functioning. Four illness identity dimensions have been identified: rejection, acceptance, engulfment, and enrichment. As longitudinal research on this topic is scarce, this study examined developmental trajectories of illness identity and prospective associations between illness identity and diabetes-specific functioning.

Methods. Adolescents and emerging adults with type 1 diabetes, aged 14 to 25 ($M_{\text{age}}=19$; 54% girls), participated in a four-wave longitudinal study spanning 3 years ($N=559$ at Time 1). Participants filled out questionnaires on illness identity, treatment adherence, and diabetes-specific distress. HbA_{1c}-values were obtained from participants’ medical records. To chart the development of illness identity over time, we performed latent growth curve modeling. Cross-lagged analysis was used to examine prospective associations between illness identity and diabetes-specific functioning.

Results. We observed small linear increases in acceptance ($M_{\text{slope}}=.05$, $p<.01$) and engulfment ($M_{\text{slope}}=.03$, $p<.05$) and a small linear decrease in rejection ($M_{\text{slope}}=-.08$, $p<.001$) across waves (with scale scores ranging between 1 and 5). Rejection negatively predicted and enrichment positively predicted treatment adherence one year later which, in turn, positively predicted enrichment and negatively predicted engulfment over time. Furthermore, rejection and engulfment positively predicted diabetes-specific distress one year later. Finally, diabetes-specific distress and HbA_{1c} positively predicted engulfment one year later. Standardized cross-lagged coefficients ranged between $|.05|$ and $|.11|$.

Conclusions. We identified small but interesting changes in three out of four illness identity dimensions. Prospective associations between illness identity and diabetes-specific functioning were bidirectional in nature.

Keywords: type 1 diabetes; chronic illness; adolescence and emerging adulthood; treatment adherence; glycemic control; illness identity; distress; latent growth curve modeling.

Introduction

Worldwide, more than a million people below the age of 20 are diagnosed with type 1 diabetes, making it one of the most common chronic illnesses in young age (International Diabetes Federation, 2019). Type 1 diabetes requires a demanding treatment regimen in which young persons need to find a delicate balance between insulin administration, food intake, and physical activity, guided by frequent blood glucose monitoring (Schneider et al., 2007). Adolescents and emerging adults often experience difficulties organizing self-management tasks or lack motivation to self-manage (Fiallo-Scharer et al., 2019). Hence, deteriorations in diabetes management and control have typically been observed during adolescence and emerging adulthood (Hilliard et al., 2013; Weissberg-Benchell et al., 2007). A recent study has shown that less than 20% of adolescents and emerging adults with type 1 diabetes actually meet treatment targets (Foster et al., 2019). This is alarming given that suboptimal glycemic control puts young persons at risk for long-term health complications and is associated with increased health care costs (Nathan, DCCT/EDIC Research Group, 2014; Wagner et al., 2001).

In addition, prior research has found a peak in psychosocial problems during adolescence and emerging adulthood (Baucom et al., 2018). This is not surprising given that these life-periods are characterized by various developmental challenges and transitions which may be difficult to reconcile with the increasing responsibilities of diabetes management (Arnett, 2000; Weissberg-Benchell et al., 2007). One such developmental challenge is building a sense of identity, which requires young persons to integrate different self-assets into a coherent sense of self and commit to important life choices and goals (Erikson, 1968). However, a chronic illness such as type 1 diabetes may challenge previously held beliefs about the self and alter plans for the future (Charmaz, 1995). Hence, young persons need to find a way to integrate their illness into their developing identity, a process captured by the concept of illness identity (Charmaz, 1983; Oris et al., 2016). Although a prior study using baseline data of the

present project has found important associations between illness identity and diabetes-specific functioning (Oris et al., 2016), there is dearth of longitudinal research on this topic. To address this gap, the present study aimed to examine (1) developmental trajectories of illness identity during the period of adolescence and emerging adulthood; and (2) prospective associations between illness identity and diabetes-specific functioning over time.

Four illness identity dimensions

Recently, an overarching framework has been developed at our center that distinguishes among four different illness identity dimensions: engulfment, rejection, acceptance, and enrichment (Oris et al., 2016, 2018). Individuals scoring high on *engulfment* feel as if their illness dominates their identity and disrupts multiple domains of daily life, which is in line with Charmaz' (1983) 'loss of self'. These individuals completely define themselves in terms of their illness, while other important self-assets or social roles – such as being a father, teacher, or football player – are set aside (Luyckx et al., 2014; Morea et al., 2008). Individuals scoring high on *rejection* typically minimize the impact of their illness on their daily lives, avoid thinking or talking about their illness, and do not take on the responsibilities of illness management (Tilden et al., 2005). These individuals tend to view their illness as a threat to their identity, resulting in poor illness integration. Individuals scoring high on *acceptance*, on the other hand, have managed to integrate their illness into their identity next to other important roles and identity commitments (Karademas et al., 2009; Luyckx et al., 2010). These individuals do not deny the existence of their illness and the associated responsibilities but they also do not feel overwhelmed or reduced to being a person with an illness. Finally, individuals scoring high on *enrichment* feel as if their illness made them a stronger person. The concept of enrichment is highly related to concepts such as benefit finding or post-traumatic growth (Rassart et al., 2017). However, whereas enrichment specifically refers to the degree to which the illness had enabled one to grow as a person, benefit finding and post-traumatic growth capture a variety of

positive changes that may occur in the context of a chronic illness (e.g., an increased appreciation for life, a closer relationship with family and friends, changed priorities, or improved coping skills) (Rassart et al., 2017; Oris et al., 2018).

Up to now, this illness identity framework has been validated in various cross-sectional studies sampling individuals with different chronic illnesses such as type 1 diabetes, refractory epilepsy, congenital heart disease, and multisystem connective tissue disorders (Luyckx et al., 2018; Oris et al., 2016, 2018). However, no study to date has examined how all four illness identity dimensions develop over the course of time in the vulnerable age group of adolescents and emerging adults. A study by Fortenberry et al. (2014) has looked at how illness perceptions develop over time in adolescents with type 1 diabetes. In this study, adolescents increasingly viewed their type 1 diabetes as chronic and having more impact. Adolescents may respond to these changing perceptions by rejecting their type 1 diabetes, because confrontation would be too threatening, or by feeling engulfed or overwhelmed (Oris et al., 2018). However, in the study by Fortenberry et al. (2014), adolescents also showed a more coherent illness understanding and felt more in control of their type 1 diabetes with increasing age, which might foster feelings of acceptance and/or reduce feelings of rejection.

Associations between illness identity and diabetes-specific functioning

Understanding the development of illness identity over time is important, as the extent to which individuals have integrated the illness into their identity has been related to a broad range of outcomes in different patient samples. For instance, in adults with refractory epilepsy, important associations were observed between illness identity and health-related quality of life, with especially higher levels of engulfment being related to a poorer quality of life (Luyckx et al., 2018). Furthermore, in adults with congenital heart disease and multisystem connective tissue disorders, higher levels of engulfment and lower levels of acceptance were related to less depressive feelings, feelings of anxiety, illness symptoms, and pain (Oris et al., 2018). Finally,

in adolescents and emerging adults with type 1 diabetes (Oris et al., 2016; Tilden et al., 2005) and adults with type 1 and type 2 diabetes (Schmitt et al., 2018), rejection has been associated with poorer treatment adherence, suboptimal glycemic control, and diabetes complications but not always with diabetes-specific distress. In contrast, acceptance has been related to better treatment adherence and less diabetes-specific distress (Commissariat et al., 2019; Oris et al., 2016; Schmitt et al., 2018). When young persons are able to accept diabetes as part of their identity, they might be better equipped to cope with diabetes-related stressors and to manage their type 1 diabetes during the challenging periods of adolescence and emerging adulthood (Luyckx et al., 2010). Similarly, enrichment has been related to higher levels of life satisfaction (Oris et al., 2016), with the broader concept of benefit finding also being associated with better treatment adherence over time (Rassart et al., 2017). Finally, as could be expected, adolescents and emerging adults with type 1 diabetes feeling engulfed by their illness have been found to experience more diabetes-specific distress (Luyckx et al., 2014; Oris et al., 2016).

Although these prior studies have provided important insights, longitudinal research is needed to examine the directionality of effects. It remains unclear whether the extent to which young persons have integrated their type 1 diabetes into their identity predicts treatment adherence, levels of distress, and glycemic control, or vice versa. Having suboptimal glycemic outcomes, experiencing high levels of distress and struggling with integrating self-care responsibilities into daily routines might also cause young persons to feel engulfed or, conversely, to reject their type 1 diabetes as part of their identity. Gaining more insight into the directionality of effects is important when designing prevention and intervention strategies.

The present study

The present study had two main objectives. Our first objective was to chart the development of illness identity over the course of the study. We hypothesized that *acceptance* would increase over this three-year period, as adolescents and emerging adults learn to

understand their type 1 diabetes and feel more in control over it (Fortenberry et al., 2014). At the same time, *engulfment* might increase as well, given that prior research found adolescents to increasingly view their type 1 diabetes as a chronic illness with serious consequences (Fortenberry et al., 2014). With regard to *rejection*, we had competing hypotheses. On the one hand, rejection could decrease over the course of the study, due to patients' greater understanding of their type 1 diabetes and higher levels of personal control. However, rejection might also increase over this three-year period, as patients feel threatened and overwhelmed by the prospect of living with a challenging, life-long illness. Finally, with regard to *enrichment*, no specific hypotheses were put forward. A recent study focusing on the related concept of benefit finding found a slight decrease in benefit finding among adolescents with type 1 diabetes (Rassart et al., 2017). However, this study focused specifically on the period of adolescence, whereas developmental trends during emerging adulthood remain relatively understudied.

In addition to charting the development of the different illness identity dimensions over time, we examined whether sex, age, illness duration, and treatment type played a role in the development of illness identity. With regard to *sex*, former findings suggest that females are somewhat more inclined to view their type 1 diabetes as central to their identity, to assume the "sick role" when ill, and to share their illness with others as compared to males (Helgeson & Novak, 2007). This may potentially result in higher levels of engulfment and lower levels of rejection among females. With regard to *age*, one might expect emerging adults to have better developed coping skills to deal with diabetes-related stressors and to integrate type 1 diabetes into their identity, although both adolescence and emerging adulthood have been described as high-risk periods in terms of diabetes adjustment (Weissberg-Benchell et al., 2007). With regard to *illness duration*, individuals diagnosed with type 1 diabetes in early childhood might have developed coping mechanisms earlier in life, fostering acceptance (Sparud-Lundin et al., 2010). Finally, with regard to *treatment type*, having an insulin pump generally increases

flexibility in eating schedules and daily life more general, which might allow adolescents and emerging adults to engage in more social activities (Weissberg-Benchell et al., 2003), potentially resulting in less rejection and/or engulfment. At present, it has not yet been examined whether illness identity develops differently at different ages and stages of the illness, in males versus females, and in patients using an insulin pump versus injections.

Our second objective was to examine prospective associations between illness identity and diabetes-specific functioning. Based on prior research, we hypothesized that higher levels of *rejection* and *engulfment* would be related to higher levels of diabetes-specific distress, poorer treatment adherence, and worse glycemic control one year later (Luyckx et al., 2014, 2018; Oris et al., 2018; Schmitt et al., 2018; Tilden et al., 2005). We expected rejection to be particularly related to treatment adherence and glycemic control (and less so to diabetes-specific distress; Benson et al., 2015; Mozzetta et al., 2008). Engulfment was expected to show the strongest associations with diabetes-specific distress. Furthermore, we hypothesized that higher levels of *acceptance* would be related to lower levels of diabetes-specific distress, better treatment adherence, and more optimal glycemic control one year later (Commissariat et al., 2019; Luyckx et al., 2010; Oris et al., 2018; Schmitt et al., 2018). Finally, we expected *enrichment* to be related to better treatment adherence one year later (Rassart et al., 2017). As discussed earlier, reverse pathways could also emerge.

Method

Participants and procedure

The present study is part of a larger project in which adolescents and emerging adults with type 1 diabetes and their parents were followed annually over a period of three years (e.g., Oris et al., 2016; Rassart et al., 2018). We recruited participants from the Belgian Diabetes Registry using the following criteria: (1) diagnosis of type 1 diabetes; (2) aged 14-25 years old; (3) sufficient cognitive abilities to fill out questionnaires; and (4) Dutch-speaking. At baseline, a package with questionnaires, an informed consent form, and a pre-stamped return envelope

were sent to 1,450 adolescents and emerging adults by post (53 of these packages were returned because of a wrong address). Participants under 18 years old were asked to complete an assent form in addition to their parents completing a consent form. The proposed study protocol was approved by the Medical Ethics Committee of the University Hospitals Leuven (Belgium).

At Time 1, a total of 570 adolescents and emerging adults returned completed questionnaires (response rate of 41%), of which 16 participants were excluded because the informed consent was lacking or because they were filled out unreliably. Hence, a total of 559 participants ($M_{\text{age}} = 18.86$ years, $SD = 3.25$; 54% girls) could be included for analyses at Time 1. Mean illness duration was 7.63 years (Range = 0-24; $SD = 4.97$). A total of 11 participants (2%) were diagnosed with type 1 diabetes less than one year prior to the start of the study. One out of five (21%) participants used an insulin pump, with the remainder prescribed multiple daily injections. A total of 422 (75%) adolescents and emerging adults participated at Time 2, 381 (68%) participated at Time 3, and 324 (58%) participated at Time 4.

No differences were observed between adolescents and emerging adults who participated at all four time-points ($n = 276$) and those who did not ($n = 283$) based on age [$F(1,557) = 0.00$, $p = .979$, $\eta^2 = .00$], age at diagnosis [$F(1,553) = 1.29$, $p = .256$, $\eta^2 = .00$], treatment type [$\chi^2(1) = 0.07$, $p = .796$], illness identity at Time 1 [$F(4,548) = 2.03$, $p = .076$, $\eta^2 = .02$], diabetes-specific distress at Time 1 [$F(1,548) = 2.93$, $p = .088$, $\eta^2 = .01$], and glycemic control at Time 1 [$F(1,420) = 2.75$, $p = .098$, $\eta^2 = .01$]. Although we did find that those participants who dropped out were more likely to be male [$\chi^2(1) = 4.07$, $p = .044$] and to show poorer treatment adherence at Time 1 [$F(1,540) = 10.13$, $p = .002$, $\eta^2 = .02$], these differences were associated with small effect sizes. Little's (1988) MCAR test was significant [$\chi^2(2626) = 2844.52$, $p = .002$], but the normed χ^2 was 1.08, indicating that data were likely missing completely at random (Bollen, 1989). Hence, we used the full information maximum likelihood (FIML) procedure in MPLUS 8.0 to deal with missing values (Enders 2010).

Measures

Illness identity. The four illness identity dimensions were measured using the 25-item Illness Identity Questionnaire (IIQ; Oris et al., 2016, 2018). Participants 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). Sample items are “My diabetes completely consumes me” (engulfment, 8 items), “I refuse to see my diabetes as part of myself” (rejection, 5 items), “I accept being a person with diabetes” (acceptance, 5 items), “Because of my diabetes, I have become a stronger person” (enrichment, 7 items). Cronbach’s alphas at Times 1-4 was .90 for engulfment and ranged between .84 and .87 for rejection, between .84 and .88 for acceptance, and between .90 and .92 for enrichment.

Diabetes-related distress. Diabetes-specific distress was measured using the Problem Areas in Diabetes Scale (PAID; Polonsky et al., 1995; Snoek et al., 2000). The PAID assesses treatment-related, food-related, emotional, and social support problems with a 5-point Likert scale ranging from 0 (not a problem) to 4 (a serious problem). Sample items are: “Feeling discouraged with your diabetes regimen (treatment), “Feelings of deprivation regarding food and meals” (food), “Feeling constantly burned out by the constant effort to manage diabetes” (emotional), and “Feeling alone with diabetes” (social support). The total score was calculated as the average of the four problem areas, with higher scores indicating more distress. Cronbach’s alphas at Times 1-4 ranged between .94 and .95.

Treatment adherence. To measure the degree to which participants followed their treatment in the past month, we used the Self-Care Inventory (SCI; Weinger et al., 2005). The SCI includes items that focus on blood glucose testing and monitoring, insulin and food regulation, exercise, and emergency precautions. We omitted the item ‘wearing a medic alert ID’, as this is not standard practice in Belgium. A mean score was calculated, with higher scores indicating better adherence. Items were answered on a five-point Likert scale from ‘never do

it' (1) to 'always do this as recommended without fail' (5). An additional 'not applicable' option was also available. Cronbach's alphas at Times 1-4 ranged between .73 and .77.

Glycemic control. HbA_{1c}-values within a time-frame of three months before or after questionnaire completion were obtained from participants' treating physicians. HbA_{1c} provides information on average blood glucose levels over the past 6-8 weeks. Values below 7.0% are typically recommended (DiMeglio et al., 2018). For analyses involving HbA_{1c}, we included only those participants with at least one HbA_{1c}-value available over the course of the study ($N = 486$). At baseline, mean HbA_{1c} was 7.7% ($SD = 1.4$) or 61 mmol/mol ($SD = 15.3$).

Statistical analysis

For Objective 1 – charting the development of the four illness identity dimensions – we used latent growth curve modeling (LGCM; McArdle, 2005) in Mplus 8.0. The path from the slope to the indicator at Time 1 was fixed to zero so that the intercept would represent the initial level. Given the equally spaced measurement intervals, subsequent linear slope pattern coefficients were fixed at 1, 2, and 3 for Times 2, 3, and 4, respectively. We first estimated an unconditional latent growth model (without covariates) to examine whether quadratic slopes were needed to model the growth in illness identity. In a next model, the role of age, sex, illness duration, and treatment type was examined by regressing the intercept and slope of each illness identity dimension on these variables. To evaluate model fit, we used standard fit indices (Kline, 2015): the Yuan-Bentler scaled chi-square statistic should be as small as possible, RMSEA should be $< .08$, SRMR should be $< .09$, and CFI should be $> .90$.

For objective 2 – examining prospective associations between illness identity and diabetes-specific functioning – we analyzed three separate cross-lagged panel models (CLPMs), one for each indicator of diabetes-specific functioning (i.e., treatment adherence, diabetes-specific distress and glycemic control), in order to keep the ratio of freely estimated parameters to cases acceptable (Kline, 2015). In each model, we included all within-time

associations, stability paths between Times 1-2, 2-3, and 3-4, cross-lagged paths among all study variables, and paths from the control variables (i.e., sex, age, illness duration, and treatment type) to the study variables at Time 1. We investigated whether identical cross-lagged paths and stability paths could be constrained as equal across time intervals by comparing a model in which cross-lagged paths and stability paths were allowed to differ across time to a model in which these paths were fixed over time. If the following criteria were satisfied, the constrained model was retained: a non-significant Yuan-Bentler scaled $\Delta\chi^2$, $\Delta\text{RMSEA} < .015$, $\Delta\text{CFI} < .010$, and $\Delta\text{SRMR} < .030$ (Chen, 2007). In all analyses, maximum likelihood estimation with robust standard errors (MLR) was used to take into account the non-normality of the data. Means and standard deviations can be found in Supplementary Table 1. Pearson correlations are displayed in Supplementary Table 2.

Results

Latent growth curve modeling

Our latent growth model including both linear and quadratic slopes provided a good fit to the data [$\chi^2(88) = 310.27$, $p < .001$, $\text{RMSEA} = .067$ [CI: .059 - .075], $\text{SRMR} = .038$, $\text{CFI} = .936$]. In a second step, quadratic slopes (which were non-significant) were removed from the model to make it more parsimonious. The model including linear slopes only [$\chi^2(92) = 314.54$, $p < .001$, $\text{RMSEA} = .066$ [CI: .058 - .074], $\text{SRMR} = .038$, $\text{CFI} = .936$] fitted the data equally well [$\Delta\chi^2(4) = 3.11$, $p = .540$, $\Delta\text{RMSEA} = .001$, $\Delta\text{SRMR} = .000$, $\Delta\text{CFI} = .000$]. Across waves, we observed significant linear increases in rejection and engulfment and a significant linear decrease in rejection. Enrichment remained relatively stable over time. These developmental trends are graphically depicted in Supplementary Figure 1. The means and variances of the intercepts and slopes are presented in Table 1.

In a third and final step, covariates (i.e., sex, age, illness duration and treatment type) were entered into the model which also resulted in a good model fit [$\chi^2(124) = 357.45$, $p < .001$, $\text{RMSEA} = .058$ [CI: .051 - .065], $\text{SRMR} = .034$, $\text{CFI} = .939$]. As shown in Table 2, several

paths from these covariates to the intercepts and slopes of the illness identity dimensions were significant. First, we found two significant paths from sex to the intercepts of acceptance and engulfment. More specifically, males generally reported higher levels of acceptance and lower levels of engulfment as compared to females. Second, we found two significant paths from age to the slopes of rejection and engulfment. Participants who were older at baseline showed a less steep decrease in rejection and a stronger increase in engulfment over time as compared to younger participants. Finally, we found a significant path from treatment type to the intercept of engulfment. More specifically, participants using an insulin pump generally showed higher levels of engulfment as compared to participants using insulin injections.

Cross-Lagged Panel Models (CLPMs)

Our first CLPM linking the four illness identity dimensions to treatment adherence over time had a good fit to the data [$\chi^2(135) = 359.73, p < .001, RMSEA = .055$ (CI: .048 - .062), SRMR = .046, CFI = .950]. Fixing cross-lagged paths and stability paths to be equal across time points did not significantly worsen model fit [$\Delta\chi^2(50) = 47.43, p = .577, \Delta RMSEA = .009, \Delta SRMR = .005, \Delta CFI = .002$] and, hence, the more parsimonious model was retained [$\chi^2(185) = 399.84, p < .001, RMSEA = .046$ (CI: .040 - .052), SRMR = .051, CFI = .952]. As shown in Figure 1 panel a, stability coefficients ranged between .52 and .69 (all $ps < .001$). Rejection negatively predicted and enrichment positively predicted treatment adherence one year later. Treatment adherence, in turn, positively predicted enrichment and negatively predicted engulfment one year later.

The second CLPM linking the four illness identity dimensions to diabetes-specific distress over time also had a good fit to the data [$\chi^2(135) = 307.72, p < .001, RMSEA = .048$ (CI: .041 - .055), SRMR = .047, CFI = .963]. Fixing cross-lagged paths and stability paths to be equal over time did not significantly worsen model fit [$\Delta\chi^2(50) = 42.04, p = .781, \Delta RMSEA = .009, \Delta SRMR = .004, \Delta CFI = .003$] and, hence, the more parsimonious model was retained

$[\chi^2(185) = 343.21, p < .001, RMSEA = .039 (CI: .033 - .046), SRMR = .051, CFI = .966]$. As shown in Figure 1 panel b, stability coefficients ranged between .52 and .70 (all $ps < .001$). Rejection and engulfment positively predicted diabetes-specific distress one year later. Diabetes-specific distress, in turn, positively predicted engulfment one year later.

The third and final CLPM linking the four illness identity dimensions to glycemic control over time had a good fit to the data $[\chi^2(135) = 333.26, p < .001, RMSEA = .055 (CI: .048 - .063), SRMR = .046, CFI = .950]$. Fixing cross-lagged paths and stability paths to be equal over time did not significantly worsen model fit $[\Delta\chi^2(50) = 61.72, p = .124, \Delta RMSEA = .007, \Delta SRMR = .013, \Delta CFI = .002]$ and, hence, the more parsimonious model was retained $[\chi^2(185) = 389.94, p < .001, RMSEA = .048 (CI: .041 - .055), SRMR = .059, CFI = .948]$. As shown in Figure 1 panel c, stability coefficients ranged between .50 and .68 (all $ps < .001$). Higher HbA_{1c} values positively predicted engulfment one year later.

Discussion

The present study is the first to date to examine developmental trajectories of illness identity and to link illness identity to diabetes-specific functioning over time in a large sample of adolescents and emerging adults with type 1 diabetes. We observed small increases in acceptance and engulfment and a small decrease in rejection across waves. Furthermore, several illness identity dimensions were prospectively related to treatment adherence, diabetes-specific distress and glycemic control, with relationships being bidirectional in nature.

Changes in illness identity over time

First, although restructuring one's identity in the face of chronic illness is generally considered a dynamic and ongoing process (Aujoulat et al., 2008), the different illness identity dimensions showed relatively high stability over the course of the study, with mean-level changes across waves (as identified through LGCM) being relatively small. Moreover, in the cross-lagged models being tested, stability coefficients ranged between .50 and .70 (all $ps < .001$).

.001), pointing to high rank-order stability. This means that the rank-order of participants – or how they score on rejection, acceptance, engulfment, and enrichment relative to others – is generally maintained over time.

Second, despite this high rank-order stability, we observed a small decrease in rejection over the course of the study, especially among younger participants, and a small increase in acceptance. These findings are in line with prior research which found adolescents with type 1 diabetes to display a more coherent illness understanding and to feel more in control of their illness with increasing age (Fortenberry et al., 2014). Furthermore, prior research has shown that adolescents who are strongly oriented towards their peers tend to neglect diabetes-related responsibilities to avoid being viewed as different (Drew et al., 2010). As adolescents approach emerging adulthood, fitting in with peers becomes less important, potentially resulting in less rejection.

Third, we observed a slight increase in engulfment over the course of study, especially among older participants. Again, this is in line with the findings of Fortenberry et al. (2014) who found that adolescents increasingly viewed their type 1 diabetes as a chronic, life-long condition with a substantial impact on daily life. Some adolescents and emerging adults may find it difficult to face this new reality and may feel overwhelmed. Especially during emerging adulthood – a period characterized by various changes, transitions, and increasing adult responsibilities (Arnett, 2000; Weissberg-Benchel et al., 2007) – young persons might feel as if their daily lives, long-term choices, and future plans are in many ways determined by their type 1 diabetes. In the qualitative study by Datye et al. (2019), some participants felt that their diabetes forced them to adjust certain life goals (such as not being able to pursue certain career paths). Hence, our findings seem to support the idea that emerging adulthood is a challenging period when it comes to integrating type 1 diabetes into one's identity.

Fourth, the illness identity dimensions did not develop differently in males vs. females. However, females did show higher levels of engulfment as compared to males. This is in line with the literature in which females have been found to assume the “sick role” more often when ill (Helgeson & Novak, 2007). As males tend to talk less to others about their type 1 diabetes and generally view their diabetes as less central to their identity (Helgeson & Novak, 2007), we tentatively expected higher levels of rejection among males. However, this was not the case; males even showed higher levels of acceptance than females.

Finally, although the illness identity dimensions did not develop differently in participants using injections vs. an insulin pump, the present study found participants on pump therapy to show higher levels of engulfment as compared to those using insulin injections. Although an insulin pump can increase feelings of normalcy because of the increased flexibility in daily life (Weissberg-Benchell et al., 2003), it can also make young persons feel different and give rise to body image concerns (Ritholz et al., 2007). In addition, patients using a pump generally need to perform more daily acts with regard to their type 1 diabetes than patients on insulin injections (e.g., bolusing). Hence, some young persons might experience their insulin pump as a constant reminder of their type 1 diabetes. In sum, the present study demonstrated that the illness identity dimensions remained fairly stable over the course of the study, although small increases in acceptance and engulfment and a small decrease in rejection were observed across waves. Illness identity did not develop differently in males vs. females, in different stages of the illness, or in patients using an insulin pump vs. injections.

Prospective associations between illness identity and diabetes-specific functioning

With regard to our second objective, we uncovered some interesting bidirectional associations between illness identity on the one hand and treatment adherence, diabetes-specific distress, and glycemic control on the other hand. First, young persons scoring higher on *rejection* at baseline showed higher levels of diabetes-specific distress one year later, as

compared to those scoring lower on rejection at baseline (but not vice versa). These young persons may try to hold on to a life without their illness to maintain a sense of normalcy (Aujoulat et al., 2008; Charmaz, 1995). Hence, some researchers have argued that rejecting the illness may serve as a strategy to avoid being emotionally overwhelmed (Benson et al., 2015; Mozzetta et al., 2008). However, rejection might only lead to a temporary relief in distress, given that the present study found rejection and distress to be positively interrelated over a 1-year period. Furthermore, in line with prior research, young persons scoring higher on rejection at baseline showed poorer treatment adherence one year later, as compared to those with lower baseline scores on rejection (Schmitt et al., 2018; Tilden et al., 2005). They tend to neglect self-care responsibilities, as they refuse to see their type 1 diabetes as part of their identity and want to lead a normal life as much as possible.

Second, somewhat surprisingly, no prospective associations were observed between *acceptance* and diabetes-specific functioning. We expected that young persons displaying higher levels of acceptance would have more inner resources to cope with diabetes-related challenges than those scoring lower on acceptance (Commissariat et al., 2019; Luyckx et al., 2010). Conversely, experiencing little diabetes-related distress and having few difficulties adhering to treatment recommendations might enhance acceptance, as the diabetes tends to interfere less with daily life (Leventhal et al., 1999; Oris et al., 2018). However, no empirical support was found for these hypotheses. By entering all four illness identity dimensions simultaneously into one model, the present study focused on unique associations between illness identity and diabetes-specific functioning. The effects of acceptance might have turned non-significant after controlling for rejection, as both dimensions were highly interrelated.

Third, we found that young persons scoring higher on *engulfment* at baseline showed higher levels of diabetes-specific distress one year later, as compared to those scoring lower on engulfment at baseline. In these persons, type 1 diabetes typically dominates one's identity and

interferes with other valued self-assets such as social relationships and work, which has been related to poorer functioning (Devins, 2010; Luyckx et al., 2014; Morea et al., 2008; Oris et al., 2016, 2018). Conversely, higher levels of diabetes-specific distress and poorer glycemic control also predicted a relative increase in engulfment one year later. Hence, experiencing diabetes-related distress (e.g., worrying about the future and the possibility of serious complications or feeling alone with diabetes) and struggling to keep HbA_{1c}-values within the optimal range may also lead to difficulties integrating type 1 diabetes into one's identity (Leventhal et al., 1999).

Finally, young persons scoring higher on *enrichment* at baseline showed better treatment adherence one year later, as compared to young persons scoring lower on enrichment at baseline. Our findings indicate that feeling enriched or experiencing personal growth may serve as a protective factor for young persons with type 1 diabetes and may motivate them to more closely follow their treatment regimen (Rassart et al., 2017). Conversely, higher levels of treatment adherence were also predictive of a relative increase in enrichment one year later. For individuals who are managing their type 1 diabetes well, it might be easier to find opportunities for personal growth than for those struggling with integrating self-care activities into daily life. In sum, the present study found some interesting associations between illness identity and diabetes-specific functioning, with relationships being bidirectional in nature.

Clinical implications

In the present study, illness identity was prospectively related to diabetes-specific distress, treatment adherence, and glycemic control. Hence, our findings may have important clinical implications. A first step might be to raise awareness in healthcare providers of the possible identity issues that some adolescents and emerging adults are facing. To assess the different illness identity dimensions, healthcare providers could use the Illness Identity Questionnaire (IIQ), a brief self-report questionnaire that has been proven valid and reliable (Oris et al., 2016). Assessing changes in IIQ scores over time (e.g., by implementing the IIQ

into a routine screening tool once a year) may give healthcare providers the opportunity to talk more directly with adolescents and emerging adults about how they have integrated type 1 diabetes into their lives. This may help these young persons to gain more insight into how they perceive themselves, and to become more aware of the impact that type 1 diabetes has on their lives. Furthermore, it may also help healthcare providers to tailor their guidance to each individual and to identify those adolescents and emerging adults in need of more specialized psychological care. Finally, given that the present study uncovered bidirectional associations between illness identity and diabetes-specific functioning, optimizing adherence and glycemic control and minimizing distress at an early age may help young persons in building a coherent identity.

Limitations and suggestions for future research

Our findings should be interpreted in light of some limitations. First, the present study generally relied on self-report questionnaires. Although this method is most suitable to gather information on internal processes such as those captured by the IIQ, future research could use additional methods. In-depth interviews, for instance, would allow for a better understanding of how type 1 diabetes fits in with the life goals and self-views of adolescents and emerging adults. Additionally, future research could benefit from including the perspectives of other important stakeholders (e.g., healthcare providers or romantic partners).

Second, several factors may limit the generalizability of our findings. Despite the fact that a large number of adolescents and emerging adults with type 1 diabetes participated in the present study, the response rate (41%) was relatively low. Unfortunately, no information was available on non-responders to examine potential sample bias. In addition, there was substantial attrition across waves. However, ancillary analyses showed that the differences between individuals participating in all four waves and those who dropped out were very limited and that data were likely to be missing completely at random. Furthermore, all participants were

sampled from the Belgian Diabetes Registry, were Dutch speaking, mostly highly educated, had the Belgian nationality, and were in relatively good glycemic control. This might have resulted in an underrepresentation of young persons experiencing serious problems (e.g., those displaying worse glycemic control). However, according to data from the Belgian Diabetes Registry, the HbA_{1c}-values in our sample were representative of the total population of 14- to 25-year olds with type 1 diabetes in the registry. Nonetheless, these HbA_{1c}-values were substantially lower than those obtained in a large sample of US samples, which might be due to multiple factors including differences in access to medical care, diabetes education, insurance coverage, eating patterns, nutrient content of meals or snacks, and level of physical activity ((Foster et al., 2019; Hermann et al., 2019). Hence, the generalizability of our findings to families in the US and other parts of the world may be limited. Future research should also replicate these findings in a sample that has more ethnic and economic diversity.

Third, we did not exclude participants who were diagnosed with type 1 diabetes less than one year prior to the start of the study. Newly diagnosed patients still have a lot to learn about their type 1 diabetes and its consequences and are only at the beginning of figuring out how to reconcile the diabetes with their existing identity (Hart et al., 2003). It would be interesting for future research to follow young persons with type 1 diabetes over longer periods of time, starting from the moment of diagnosis, to examine how the different illness identity dimensions develop across different stages of the illness.

Fourth, all coefficients obtained through latent growth curve modeling and cross-lagged analysis were relatively small. However, whereas some may discount small effects as trivial, in longitudinal studies, they often are meaningful (Adachi and Willoughby, 2014). Given that many variables within the field of psychology show strong stability over time (which is also the case in our study), controlling for stability effects often removes a large portion of variance in the outcome that is shared with the predictors (Adachi & Willoughby, 2014). In our CLPMs, we

controlled for all within-time associations, stabilities, effects of the control variables, and even cross-lagged associations among the different illness identity dimensions (which were highly interrelated), strongly reducing the amount of variability that can be explained by other variables. Hence, given the conservative nature of such analyses, we believe that the small coefficients that were obtained in the present study are still meaningful.

Fifth, more recently, some authors have point out that the traditional CLPM does not distinguish between within-person and between-person variance, which may lead to erroneous conclusions (Hamaker et al., 2015). To investigate potential within-person associations, we extended our CLPMs to random intercept cross-lagged panel models (RI-CLPMs). Whereas traditional CLPMs are used to examine changes in rank order over time, RI-CLPMs are used to test within-person changes. In RI-CLPMs, the variance of each variable is split into a stable time-invariant trait-like part (captured with random intercepts) and within-person fluctuations from measurement to measurement around the person's own expected score (Masselink et al., 2018). Although our RI-CLPMs fitted the data well, none of the cross-lagged coefficients linking illness identity to diabetes-specific functioning were found to be significant (more details on these analyses can be obtained from the first author). Orth et al. (2020) argued that the cross-lagged effects captured by the RI-CLPMs are typically less consistent and more short-term compared to the cross-lagged effects captured by the traditional CLPMs. This also suggests that when using RI-CLPMs, shorter time lags between assessments (i.e., a few days, weeks, or months) are needed to be able to detect prospective within-person effects (Orth et al., 2020). Hence, future research should use intensive, short-term diary studies assessing variables on a daily basis to capture such effects.

Furthermore, Orth et al. (2020) indicated that, although it is useful to distinguish between within-person and between-person differences, the traditional CLPM can answer questions that cannot be addressed with models focusing on within-person effects. More

specifically, studies exploring risk and resilience factors typically focus on between-person processes (i.e., do people scoring high on a risk factor show worse developmental outcomes than people low on the risk factor), which are captured best by a traditional CLPM. Similarly, the present study examined, for instance, whether participants having higher baseline scores on rejection would show a relative decrease in treatment adherence one year later, compared to participants with lower rejection scores at baseline. Hence, although we acknowledge the strengths of the RI-CLPM, we believe that the traditional CLPM provides a better fit with our research objectives and is more suitable given that our study design (with its relatively long time intervals) has not been set up to capture such time-lagged within-person effects.

Finally, our findings indicate that there might be some degree of conceptual overlap between acceptance and rejection, given that both dimensions were highly interrelated (r s ranging from $-.64$ to $-.69$ across waves) and associations between acceptance and diabetes-specific functioning turned non-significant after controlling for rejection. Although prior research in different chronic illness samples (including type 1 diabetes) has provided support for the four-factor structure of the IIQ, future research might want to look into this issue more closely (Luyckx et al., 2018; Oris et al., 2016, 2018).

In sum, this study was the first to examine developmental trajectories of illness identity and to link illness identity and diabetes-specific functioning over time in a large sample of adolescents and emerging adults with type 1 diabetes. We hope that our findings may provide avenues for future research and help raise awareness among healthcare providers of the identity issues that some young persons are facing in living with their type 1 diabetes on a daily basis.

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Supplementary Table 1

Means and Standard Deviations (Between Brackets) for all Study Variables at T1-4

	Time 1	Time 2	Time 3	Time 4
Rejection	2.24 (0.99)	2.21 (0.96)	2.03 (0.93)	1.96 (0.87)
Acceptance	3.83 (0.95)	3.85 (0.94)	4.00 (0.88)	4.00 (0.81)
Engulfment	2.19 (0.87)	2.12 (0.81)	2.21 (0.83)	2.23 (0.82)
Enrichment	2.95 (0.97)	3.00 (0.94)	2.95 (0.94)	3.01 (0.96)
Treatment adherence	3.74 (0.54)	3.77 (0.55)	3.75 (0.54)	3.76 (0.50)
Diabetes-specific distress	1.01 (0.79)	0.92 (0.75)	0.90 (0.75)	0.85 (0.74)
HbA _{1c}	7.74 (1.43)	7.74 (1.27)	7.60 (1.12)	7.68 (1.14)

Supplementary Table 2

Correlations Among all Study Variables at T1-4

	Rejection	Acceptance	Engulfment	Enrichment	Adherence	Distress	HbA_{1C}
Rejection	.72***/.76*** .77***						
Acceptance	-.64***/-.68*** -.68***/-.69***	.67***/.71*** .76***					
Engulfment	.49***/.41*** .45***/.44***	-.54***/-.46*** -.43***/-.39***	.66***/.74*** .73***				
Enrichment	-.32***/-.37*** -.29***/-.37***	.38***/.38*** .33***/.41***	-.09*/-.02 .06/.04	.69***/.73*** .76***			
Adherence	-.32***/-.25*** -.25***/-.29***	.31***/.26*** .23***/.27***	-.21***/-.11* -.10/-.09	.18***/.24*** .20***/.28***	.68***/.61*** .73***		
Distress	.41***/.42*** .47***/.44***	-.53***/-.47*** -.48***/-.44***	.59***/.56*** .58***/.58***	-.11*/-.10* -.07/-.08	-.36***/-.20*** -.27***/-.24***	.65***/.65*** .75***	
HbA_{1C}	.23***/.22*** .21***/.28***	-.20***/-.25*** -.23***/-.25***	.17***/.21*** .22***/.14	-.15**/-.11 -.03/-.14*	-.27***/-.21*** -.24***/-.25***	.17**/.21*** .23***/.13	.70***/.63*** .70***

Note. The first coefficient is for Time 1, the second for Time 2, the third for Time 3, and the fourth for Time 4. On the diagonal, test-retest correlations are displayed, with the first coefficient representing the stability from Time 1 to Time 2, the second coefficient representing the stability from Time 2 to Time 3, and the third coefficient representing the stability from Time 3 to Time 4. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 1

Final Parameter Estimates of Latent Growth Curve Modeling on Illness Identity

	Rejection	Acceptance	Engulfment	Enrichment
Means				
Intercept	2.27*** (.04)	3.82*** (.04)	2.17*** (.04)	2.95*** (.04)
Linear slope	-.08*** (.02)	.05** (.01)	.03* (.01)	.00 (.01)
Variiances				
Intercept	.76*** (.06)	.67*** (.06)	.52*** (.05)	.66*** (.05)
Linear slope	.04*** (.01)	.04*** (.01)	.03** (.01)	.03** (.01)

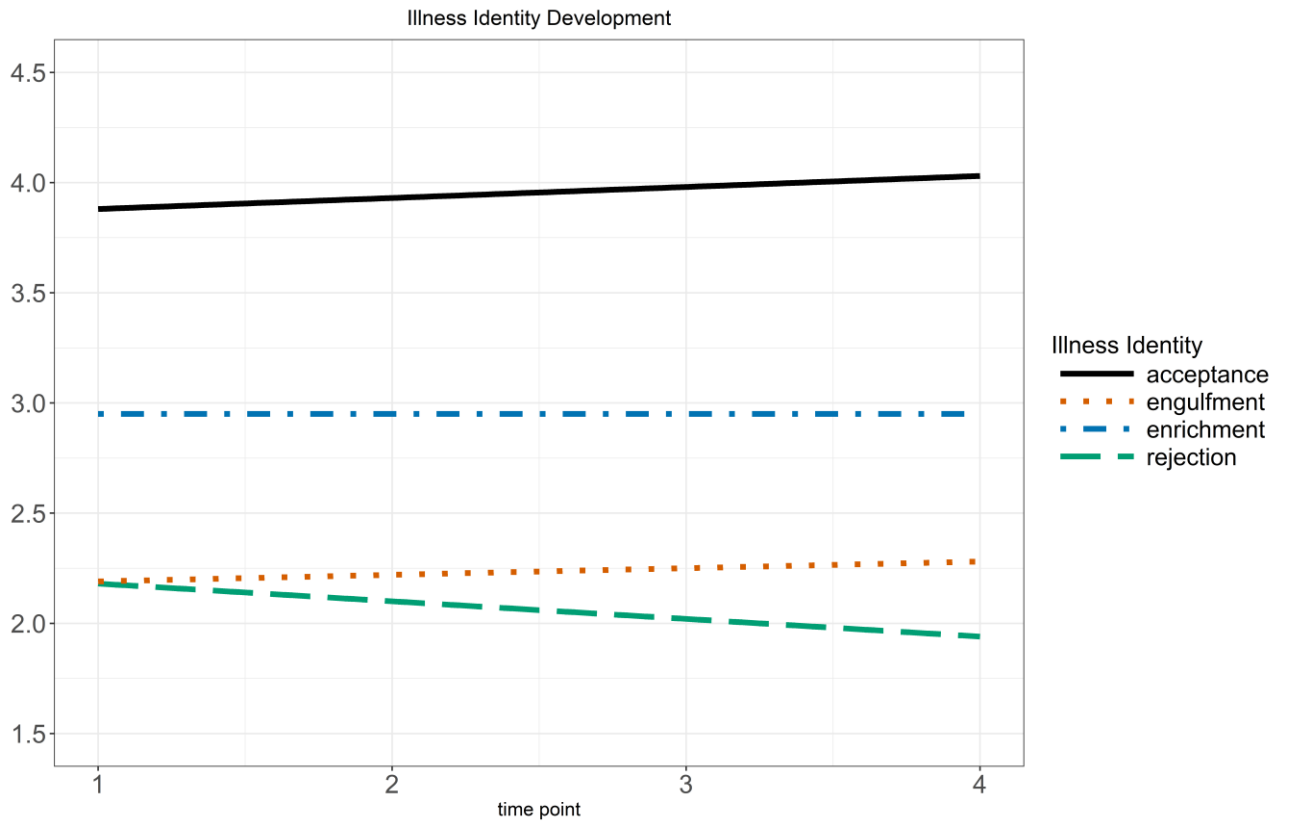
Note. Standard errors between brackets. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 2

Path Coefficients from Regressing the Intercept and Slope of Each Illness Identity Dimension on the Control Variables

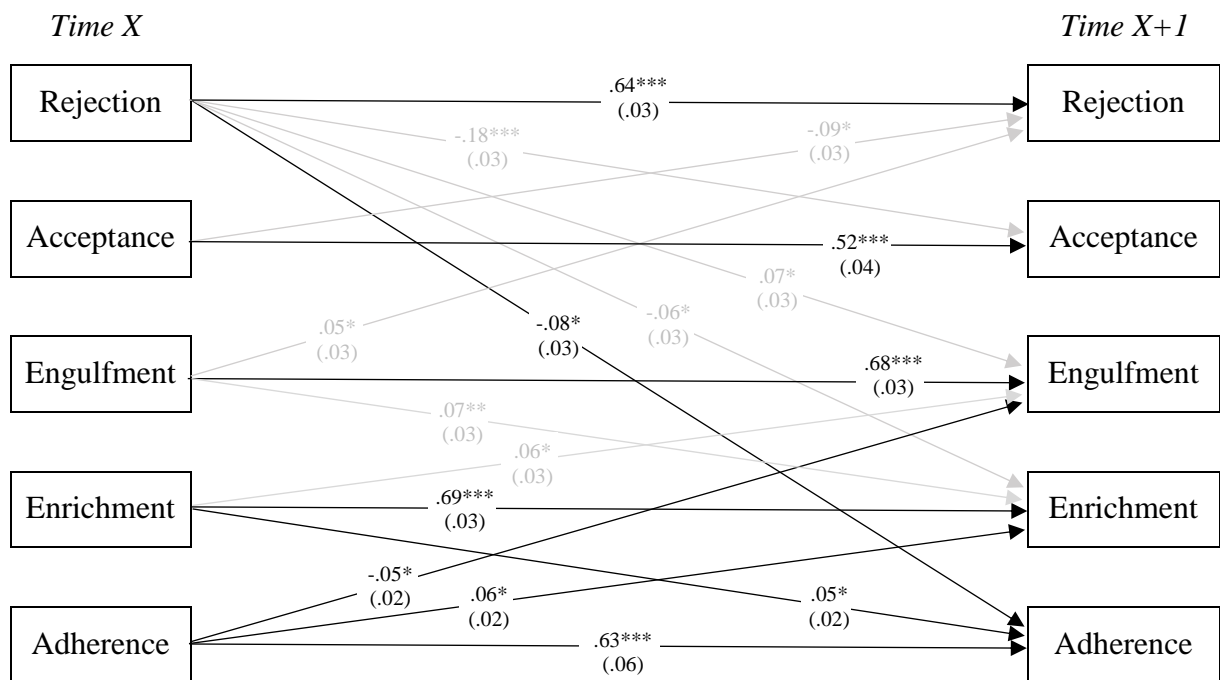
	Rejection		Acceptance		Engulfment		Enrichment	
	I	S	I	S	I	S	I	S
Age	-.08 (.05)	.20* (.08)	-.05 (.05)	-.03 (.07)	-.04 (.05)	.20* (.08)	-.06 (.05)	-.06 (.08)
Sex	.07 (.05)	.05 (.07)	-.19*** (.05)	.09 (.07)	.13** (.05)	-.02 (.08)	.05 (.05)	.02 (.09)
Illness duration	-.06 (.05)	.01 (.07)	.07 (.05)	.04 (.07)	-.07 (.05)	.15 (.07)	-.06 (.05)	.03 (.08)
Treatment type	-.03 (.05)	.05 (.07)	-.03 (.05)	.07 (.07)	.12* (.05)	-.09 (.09)	.02 (.05)	-.05 (.08)

Note. I = Intercept; S = Linear slope. Standard errors between brackets. * $p < .05$, ** $p < .01$, *** $p < .001$.

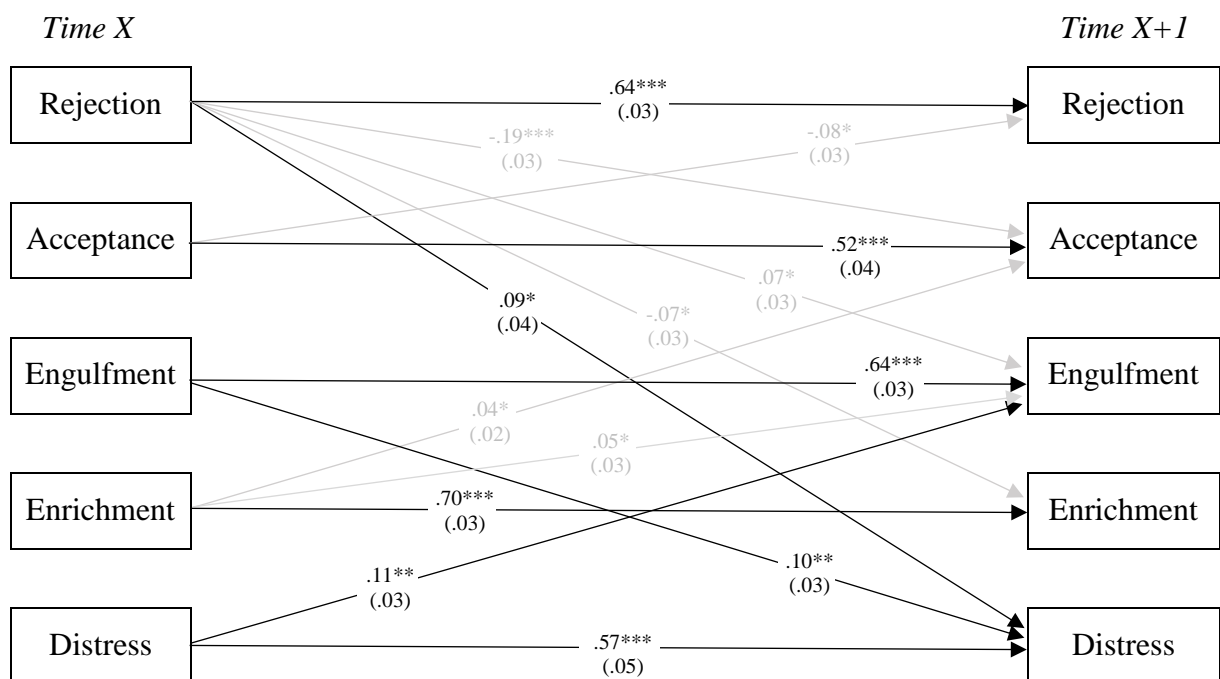


Supplementary Figure 1. Estimated means for the four illness identity dimensions from Time 1-4. Scales range from 1 to 5.

Panel a



Panel b



Panel c

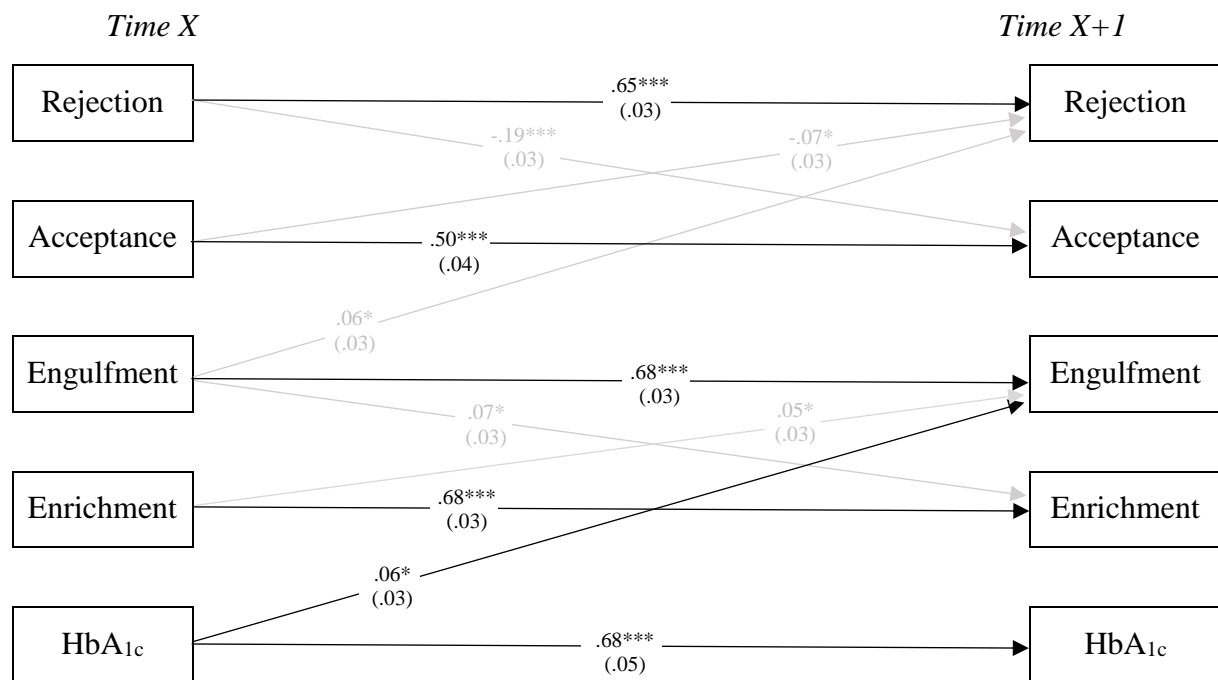


Figure 1. Cross-lagged analysis linking illness identity to diabetes-specific functioning over time. For reasons of clarity, within-time associations and paths from the control variables are not presented in the figures. Cross-lagged paths among the illness identity dimensions are in grey, as they are not the main focus of the present manuscript. All coefficients are standardized. Standard errors are presented between brackets.

* $p < .05$, ** $p < .01$, *** $p < .001$.