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Illness Identity in Adults with a Chronic Illness

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Abstract

Objective. The present study examines the concept of illness identity, the degree to which a chronic illness is integrated into one’s identity, in adults with a chronic illness by validating a new self-report questionnaire, the Illness Identity Questionnaire (IIQ). **Methods.** Self-report questionnaires on illness identity, psychological and physical functioning were assessed in two samples: adults with congenital heart disease (22-78 year old; $n=276$) and with multisystem connective tissue disorders (systemic lupus erythematosus or systemic sclerosis; 17-81 year old; $n=241$). **Results.** The IIQ could differentiate four illness identity states (i.e., engulfment, rejection, acceptance, and enrichment) in both samples, based on exploratory and confirmatory factor analysis. All four subscales proved to be reliable. Rejection and engulfment were related to maladaptive psychological and physical functioning, whereas acceptance and enrichment were related to adaptive psychological and physical functioning. **Conclusion.** The present findings underscore the importance of the concept of illness identity. The IIQ, a self-report questionnaire, is introduced to measure four different illness identity states in adults with a chronic illness.

KEYWORDS: chronic illness, congenital heart defects, multisystem connective tissue disorders, illness identity, psychological functioning

42

Introduction

43 Having a chronic illness can pose major challenges to a person's life due to many lifestyle
44 changes, such as adhering to a daily treatment regimen. Although most patients succeed in adjusting
45 to their illness, some patients experience substantial difficulties, which can negatively affect their
46 physical and psychosocial functioning (Morea, Friend, & Bennett, 2008). To understand why some
47 patients succeed in managing these challenges, whereas others experience more difficulties, the
48 present study examined the concept of illness identity from an integrative point of view. In line with
49 Charmaz (1995), we define illness identity as the degree to which a chronic illness becomes integrated
50 into one's identity (Oris et al., 2016). Four different illness identity states were distinguished (i.e.,
51 rejection, engulfment, acceptance, and enrichment) and their relation to psychological and physical
52 functioning was examined.

53 *Illness Identity in Chronic Illness*

54 Inspired by Erikson's (1968) seminal work on lifespan ego-development, identity is viewed as
55 the degree to which (i) an individual (manages to) integrates different self-assets into a coherent sense
56 of self, and (ii) such a coherent sense of self translates itself into daily life and guides choices and
57 values. This gives rise to a feeling of continuity and sameness and has been demonstrated to contribute
58 to psychological well-being (Campbell, Assanand, & Paula, 2003; Erikson, 1968; Schwartz, 2001). When
59 confronted with a chronic illness, individuals need to understand what this means to their identity and
60 try to create or regain a coherent sense of self (Leventhal, Idler, & Leventhal, 1999). In other words,
61 they need to integrate their chronic illness into their identity, a process originally conceptualized as
62 illness identity in the sociological literature (Charmaz, 1995). Over the years, many related constructs
63 from different theoretical backgrounds have been forwarded related to the topic of illness identity.
64 Only recently, to bridge these traditions, Oris et al. (2016) have introduced and validated a new
65 questionnaire, the Illness Identity Questionnaire (IIQ), in youth (ages 14-25) with type 1 diabetes (T1D).
66 The IIQ extends the Illness Self-Concept Scale, which assesses engulfment and acceptance on one
67 dimension (Morea et al., 2008), by explicitly distinguishing among these states and by adding two

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68 additional constructs that have been suggested by Charmaz (1999) and have demonstrated to be also
69 important (Senol-Durak, 2014; Tilden, Charman, Sharples, & Fosbury, 2005): rejection and enrichment.
70 Hence, The IIQ focuses on four different illness identity states: rejection, engulfment, acceptance, and
71 enrichment. The first two identity states assessed by the IIQ, *engulfment* and *rejection*, capture a lack
72 of illness integration (Oris et al., 2016). *Engulfment* refers to the degree to which chronic illness
73 dominates a person's identity and daily life. Individuals completely define themselves in terms of their
74 illness, which invades all domains of life, at the expense of other important self-assets (Morea et al.,
75 2008). Next, the state of *rejection* is mainly based on qualitative studies that tried to understand poor
76 treatment adherence in patients with T1D and asthma (Adams, Pill, & Jones, 1997; Tilden et al., 2005).
77 These studies concluded that some patients tend to neglect their illness, resulting in suboptimal
78 treatment adherence (Oris et al., 2016). These individuals also try to avoid thinking and talking with
79 others about their illness (Tilden et al., 2005). Hence, *rejection* refers to the degree to which the chronic
80 illness is rejected as part of one's identity and is viewed as a threat or as being unacceptable to the
81 self.

82 In contrast to these two illness identity states, two other states capture ways of adaptive illness
83 integration: *acceptance* and *enrichment* (Oris et al., 2016). *Acceptance* captures the degree to which
84 individuals accept the illness as part of their identity without being overwhelmed. Chronic illness plays
85 a peripheral role in one's identity, besides other personal, relational, and social self-assets, and does
86 not pervade all life domains (Morea et al., 2008). Patients try to lead as normal a life as possible,
87 whereas, at the same time, they do not deny having a chronic illness (Adams et al., 1997). Finally, with
88 respect to the fourth illness identity resolution (*enrichment*), positive changes as a result of negative
89 life events, such as chronic illness, have been referred to as benefit finding or stress-related growth
90 (Helgeson, Reynolds, & Tomich, 2006; Senol-Durak, 2014). Such positive changes manifest themselves
91 in different ways, including an increased appreciation for life, changed life priorities, increased
92 personal strength, and more positive interpersonal relationships (Tedeschi & Calhoun, 2004). In
93 contrast to the broader concepts of benefit finding or post-traumatic growth, *enrichment* specifically

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94 refers to positive changes related to one's identity. Hence, it refers to the degree to which chronic
95 illness enriches one's sense of self, and enables one to grow as a person.

96 Although these four concepts have been examined previously (e.g., Evers et al., 2001; Helgeson
97 et al., 2006; Morea et al., 2008; Tilden et al., 2005), no study or existing questionnaire assessed these
98 four illness identity states simultaneously and/or forwarded an integrative framework. For example,
99 the Illness Cognition Questionnaire (Evers et al., 2001) focused on helplessness (which is somewhat
100 similar to engulfment), acceptance, and perceived benefits, but did not assess rejection. Although
101 previous measures have substantially improved our understanding of illness identity, the IIQ, which
102 taps into these four illness identity states, allows fine-tuning the assessment of illness identity. Hence,
103 the concept of illness identity could provide an integrative framework, potentially guiding both
104 research and clinical practice.

105 ***Psychological and Physical functioning***

106 Attaining an identity structure in which different self-assets are integrated into a coherent
107 whole has been found to contribute to psychological well-being (Campbell et al., 2003). Hence, the
108 degree to which individuals achieve to attain such a coherent identity in the context of chronic illness
109 may influence psychological functioning as well (Morea et al., 2008). As such, rejection may give rise
110 to suboptimal functioning, as a potentially important self-asset is being ignored (Baumeister, 1999).
111 Also, a chronic illness that intrudes upon all life domains (cf. engulfment) has demonstrated to be
112 related to maladaptive functioning (Luyckx, Rassart, & Weets, 2015; Oris et al., 2016). In contrast,
113 acceptance and enrichment have been related to adaptive psychological functioning (Helgeson et al.,
114 2006; Oris et al., 2016).

115 In addition, the degree to which individuals integrate a chronic illness into one's identity might
116 relate to physical functioning as well (Leventhal et al., 1999). As physical symptoms may disrupt
117 everyday functioning, they may interfere with identity roles and instigate individuals to rethink one's
118 identity (Leventhal et al., 1999). In addition, illness identity may also influence physical functioning and
119 symptom experience (Leventhal et al., 1999; Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010). For

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120 example, acceptance of the illness as part of one's identity might lead to more adaptive better coping
121 and self-care (Richardson, Adner, & Nordstrom, 2001) and, hence, better (perceived) physical health
122 (Karademas, Tsagaraki, & Lambrou, 2009). Research has indeed demonstrated that acceptance was
123 related to less illness symptoms, whereas concepts related to engulfment were related to more
124 symptoms (Evers et al., 2001; Morea et al., 2008).

125 ***Research Objectives and Hypotheses***

126 The present study aims to provide evidence for the concept of illness identity in adults with
127 chronic illness by assessing the validity of these four states and by examining associations with
128 psychological and physical functioning. In examining our research objectives, two patient samples
129 were used: congenital heart disease (CHD) and multisystem connective tissue disorders (MSDs). First,
130 CHD is the most frequent birth defect (9:1,000 births; van der Linde et al., 2011) and comprises a wide
131 spectrum of structural heart lesions, varying from simple to complex severity lesions (Vander Velde et
132 al., 2005). Because almost 90% of children with CHD survive into adulthood (Moons, Bovijn, Budts,
133 Belmans, & Gewillig, 2010), a long-term follow-up throughout the lifespan is needed to decrease rates
134 of morbidity and mortality (Warnes et al., 2008). Hence, although adults with CHD generally manage
135 to successfully engage in different adult life responsibilities and roles, they are also confronted with
136 various medical, psychosocial, and behavioral challenges, such as restricted employment opportunities
137 because of physical limitations (Kovacs, Sears, & Saidi, 2005).

138 Second, MSDs are chronic auto-immune conditions characterized by a complex pathogenesis
139 and inflammation of multiple organ systems (Medsger, 2003; Simard & Costenbader, 2007). The
140 present study focuses on two such MSDs: Systemic lupus erythematosus (SLE) and Systemic sclerosis
141 (SSc). SLE is a systemic auto-immune disease which has a highly variable course and prognosis. It is
142 characterized by, for instance, organ involvement, but also by joint and muscle pains, skin rashes, and
143 fatigue (Simard & Costenbader, 2007). SSc is characterized by three cardinal pathogenic features:
144 activation of the immune system, fibrosis of the skin and internal organs, and microvascular
145 involvement (Medsger, 2003). Prevalence rates of both diseases vary greatly geographically, with

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146 ranges from 1.4-21.9/100,000 inhabitants for SLE and from 7-700/1,000,000 for SSc. Both diseases
147 occur primarily in women (male-to-female ratio of about 9:1 in SLE and 3:1 to 8:1 in SSc), with usual
148 disease onset between ages 15 and 40 in SLE and between ages 35 and 55 in SSc (Lisnevskaja, Murphy,
149 & Isenberg; Simard & Costenbader, 2007; Valentini & Black, 2002). Given the heterogeneous and
150 unpredictable disease course, with high morbidity rates and high mortality rates in the case of SSc,
151 both disorders have a substantial impact on daily life (Dobkin, Da Costa, & Dritsa, 1999;
152 Haythornthwaite, Heinberg, & McGuire, 2003). Although CHD and MSDs are different medical
153 conditions, both groups of patients are confronted with common challenges, such as lifestyle changes
154 and recognizing symptoms related to their condition. Research has indeed demonstrated that chronic
155 illnesses have general stressors and tasks in common, although differences in the degree and type of
156 stressors do exist (Heijmans et al., 2004). Hence, in the present study, integration of chronic illness into
157 one's identity is viewed as a common task across diagnostic categories (Schulman-Green et al., 2012).

158 *Objective 1: Factorial Validity and Reliability of the IIQ*

159 Given that subscale scores on the IIQ have only been validated in youth with T1D (Oris et al.,
160 2016) and illness integration is a lifelong challenge and process (Leventhal et al., 1999; Schulman-
161 Green et al., 2012), our first objective was to validate subscale scores on the IIQ in adults with CHD and
162 MSDs. Furthermore, internal consistencies of the four illness identity states were examined.

163 *Objective 2: Associations with Demographic and Clinical Parameters*

164 The present study explored mean differences in illness identity states based on demographic
165 and clinical variables. First, based on a recent study on illness identity (Oris et al., 2016), no sex and
166 age differences in illness identity were expected (Oris et al., 2016). Second, in patients with MSDs,
167 disease duration was expected to be unrelated to illness identity (Oris et al., 2016). As the study by
168 Oris et al. (2016) focused on youth (ages 14-25), we aimed to explore if consistency of the results for
169 sex, age, and disease duration could be demonstrated in adults. Third, we explored mean differences
170 in illness identity states between patients with CHD and MSDs. As these patient groups have not been
171 directly compared before, we did not have specific hypotheses. Finally, we compared differences

172 within conditions. Complex heart defects and SSc could lead to greater disruptions in a person's life as
173 compared to simple/moderate heart defects and SLE, respectively (Haythornthwaite et al., 2003;
174 Kovacs et al., 2005), possibly leading to engulfment (Beanlands et al., 2003). Such disruptions could
175 also increase the odds that the chronic illness would be rejected as part of one's identity, as
176 confrontation would be too overwhelming (Mozzetta et al., 2008). However, as self-growth is more
177 likely to occur with more severe stressors (Helgeson et al., 2006), complex heart defects and SSc could
178 lead to feelings of enrichment as well. Consequently, patients with a more complex heart defect and
179 with SSc were expected to score higher on engulfment, rejection, and enrichment than patients with
180 a simple defect and SLE, respectively.

181 *Objective 3: Associations with Psychological and Physical Functioning*

182 Depressive and anxiety symptoms were used as an indicator of psychological functioning in
183 both patient groups. Perceived illness symptoms and pain were used as an indicator of perceived
184 physical functioning in patients with CHD and MSDs, respectively. We expected rejection and
185 engulfment to be positively related to depressive and anxiety symptoms (Oris et al., 2016), and, for
186 engulfment, also to illness symptoms and pain (Morea et al., 2008). Acceptance and enrichment would
187 be negatively related to depressive and anxiety symptoms (Oris et al., 2016), and for acceptance, also
188 to illness symptoms, and pain (Evers et al., 2001).

189 **Methods**

190 ***Participants and Procedure***

191 *Sample 1.* As part of the Belgian branch of APPROACH-IS (Assessment of Patient-Reported
192 Outcomes in Adults with Congenital Heart Disease – International Study; Apers et al., 2015, 2016),
193 patients were selected from the database of congenital cardiology of the University Hospitals Leuven
194 (Belgium) using the following criteria: (1) diagnosis of CHD, defined as a structural abnormality of the
195 heart and/or intra-thoracic great vessels present at birth and actually or potentially functionally
196 significant (including mild, moderate, and severe heart defects; Mitchell, Korones, & Berendes, 1971);
197 (2) born before 1991; (3) diagnosis established before the age of 10 (i.e., before adolescence to warrant

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198 sufficient experience of living with CHD); (4) continued follow-up at our center; and (5) physical,
199 cognitive, and language capabilities required to complete the self-report questionnaires. Patients are
200 excluded from study participation if they (1) underwent prior heart transplantation; (2) have primary
201 pulmonary hypertension; or (3) have impaired cognitive abilities. A total of 400 patients who fulfilled
202 these criteria were randomly selected to participate, of which 377 (94%) were retained after a final
203 check of the criteria. All participants received a postal study package including: (1) a study information
204 letter; (2) a copy of the survey package; (3) the informed consent form; and (4) an addressed, pre-
205 stamped return envelope. A total of 276 patients (54.3% men; response rate: 73.2%) returned
206 completed questionnaires. Demographic characteristics are presented in Table 1. Age ranged from 22
207 to 78 years ($M=36.8$, $SD=11.4$). The complexity of heart defects was determined based on Task Force
208 1 of the 32nd Bethesda conference as simple (33.7% of the sample), moderate (54.3%), or complex
209 (12%) (Warnes et al., 2001).

210 *Sample 2.* Patients were selected from the database of rheumatology of the University
211 Hospitals Leuven using the following criteria: (1) diagnosis of SLE or SSc, (2) Dutch-speaking, (3) the
212 patient is able to fill in an informed consent form, (4) the patients' cognitive or medical condition allows
213 for filling out the questionnaire, and (5) absence of a severe psychiatric disorder. A total of 285 patients
214 fulfilled these criteria, who all received a postal study package including: (1) a study information letter;
215 (2) a copy of the survey package; (3) the informed consent form; and (4) an addressed, pre-stamped
216 return envelope. A total of 241 patients (17.4% men; response rate: 85%) returned completed
217 questionnaires (53.1% patients with SLE). Demographic characteristics are presented in Table 1. Age
218 ranged from 17 to 81 years ($M=52.8$, $SD=14.9$). Mean disease duration was 11.36 years ($SD = 9.60$).
219 Informed consent was obtained from all individual participants included in both studies. All procedures
220 performed in both studies involving human participants were in accordance with the ethical standards
221 of the institutional and/or national research committee and with the 1964 Helsinki declaration and its
222 later amendments or comparable ethical standards.

223 **Measures**

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224 *Illness identity.* The Illness Identity Questionnaire (IIQ) was used to assess the four illness
225 identity states (Oris et al., 2016). Eight items were initially formulated for each of the illness identity
226 states: rejection, engulfment, acceptance, and enrichment. This item pool was generated based on a
227 broad literature search into existing measures focusing on illness identity or related constructs (e.g.,
228 Illness Cognition Questionnaire; Evers et al., 2001). Further, newly generated items, which were
229 semantically based on these measures, were also included in this initial item pool. Patients were asked
230 to indicate how much they agreed with each statement on a 5-point Likert scale ranging from 1
231 (*strongly disagree*) to 5 (*strongly agree*).

232 *Depressive and anxiety symptoms.* Depressive and anxiety symptoms were measured with the
233 depression and anxiety subscales of the Hospital Anxiety and Depression Scale (HADS; Spinhoven et
234 al., 1997; Zigmond & Snaith, 1983), which consists of seven items for each subscale with a 4-point scale
235 ranging from 0 to 3. Scores can range from 0 to 21, with high scores indicating more depressive and
236 anxiety symptoms. Sample items are “I still enjoy the things I used to enjoy” (depressive symptoms)
237 and “I get a sudden feeling of panic” (anxiety symptoms). Cronbach’s alpha’s for depressive and
238 anxiety symptoms, were .83 and .87 in patients with CHD and .84 and .85 in patients with MSDs,
239 respectively.

240 *Physical functioning.* Physical functioning, as subjectively experienced by the patient, was
241 assessed with a single item. Patients with CHD responded to the item “How much do you experience
242 symptoms from your illness” (illness symptoms) of the Brief Illness Perception Questionnaire, on a 0-
243 10 response scale (Broadbent, Petrie, Main, & Weinman, 2006; de Raaij, Schroder, Maissan, Pool, &
244 Wittink, 2012). Patients with MSDs responded to the pain/discomfort item of the EQ-5D-5L on a 5-
245 point scale from “I have no pain or discomfort” to “I have extreme pain or discomfort” (Herdman et
246 al., 2011).

247 ***Statistical Analysis***

248 Analyses were conducted in three steps, according to the three main objectives. First, we conducted
249 principal axis factoring with promax rotation in Sample 1 on the 32 items of the IIQ using SPSS 23

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250 (Brown, 2015). Both the scree test (Cattell, 1966) and parallel analysis (using the 95th percentiles of
251 the distributions of eigenvalues; Buja & Eyuboglu, 1992; Horn, 1965) were used to select the
252 appropriate number of factors (Brown, 2015; Worthington & Whittaker, 2006). All items with loadings
253 less than .40 on their intended factor and/or with cross-loadings exceeding $|.32|$ were deleted in a
254 stepwise approach, because such items could be poor indicators of the intended factor (Brown, 2015;
255 Worthington & Whittaker, 2006). Next, to evaluate the model fit of the factor solution based on EFA,
256 we conducted Confirmatory Factor Analysis (CFA) using Mplus 7 in Sample 2. To deal with non-normal
257 data distributions, Maximum Likelihood Mean Variance (MLMV) was used as a robust estimation
258 method (Kline, 2005). To evaluate model fit, we used the χ^2 -index, which should be as small as possible.
259 Given that χ^2 -index is sensitive to sample size (i.e., it becomes significant with large sample size; Hu &
260 Bentler, 1999), we additionally used the normed χ^2 (χ^2/df), which should be less than 2 (Ulman, 2013),
261 and used alternative fit indices (Brown, 2015; Kline, 2005): the Root Mean Square Error of
262 Approximation (RMSEA), which should be less than .08; the Comparative Fit Index (CFI), which should
263 exceed .90; and the Standardized Root Mean Square Residual (SRMR), which should be less than .09
264 (Kline, 2005). Second, multivariate analyses of variance (MANOVA), using Wilks' Lambda, were used to
265 test for mean differences in illness identity (as dependent variable) based on sex, condition (CHD or
266 MSDs), disease complexity in CHD, and diagnosis (SSc or SLE) in MSDs. For age and disease duration,
267 Pearson correlation coefficients were calculated with the four illness identity states. Third, to examine
268 the associations linking illness identity to psychological and physical functioning, Pearson correlation
269 coefficients were calculated (if age and gender correlate significantly with illness identity, partial
270 correlations would be calculated).

271 **Results**

272 ***Objective 1: Factorial Validity and Reliability of the IIQ***

273 *Exploratory Factor Analysis in Sample 1*

274 *Factor retention.* Based on the scree test four factors were retained. Based on parallel analysis, using
275 the 95th percentiles of the distributions of eigenvalues (Buja & Eyuboglu, 1992; Horn, 1965), seven

276 factors needed to be retained. However, based on recommendations of Brown (2015), a number of
277 interrelated reasons seemed to indicate that seven would be too many factors to use in our case. First,
278 and foremost, on three of the seven factors only two items had salient loadings, which means these
279 factors are poorly defined and can be eliminated. Second, a limitation of Exploratory Factor Analysis
280 (EFA) is that correlated indicator errors cannot be included. Hence, EFA may suggest more factors while
281 the relationships between some items (indicators) may be better explained by correlated errors
282 signalling method effects rather than additional latent factors. Third, some authors argue that parallel
283 analysis using principal axis factoring tends to select too many factors (Buja & Eyuboglu, 1992). As such,
284 combining these three considerations, a more parsimonious four-factor solution is preferred. Hence,
285 we could conclude that four factors needed to be retained based on exploratory factor analysis.

286 *Item retention or deletion.* A total of five items had to be deleted, two items because of no
287 loading above .40 and three items because of a negative cross-loading. Hence, the item pool was
288 reduced to 27 items. Two additional items with relatively low loadings were deleted based on
289 conceptual grounds as well. The final four-factor solution, which explained 60.81% of the variance,
290 consisted of a 7-item enrichment scale, an 8-item engulfment scale, a 5-item acceptance scale, and a
291 5-item rejection scale. Factor loadings are given in Table 2.

292 *Confirmatory Factor Analysis in Sample 2*

293 After including three error correlations (based on the highest modification indices) between
294 items that are somewhat similarly worded (i.e., method effect for items 6 – 7, items 17 – 18, and items
295 24 – 25; Brown, 2015), the four-factor model provided an adequate fit to the data of patients with
296 MSDs ($df=266$; $\chi^2=382.82$, $p<.001$, $\chi^2/df=1.44$; RMSEA=.046; CFI=.909; SRMR=.067)⁷. Further, all three-
297 factor models demonstrated poor fit to the data and, based on Bayesian Information Criteria and χ^2

⁷ Additionally, CFA was conducted in sample 1 (CHD) and full measurement invariance (i.e., configural, metric, and scalar invariance) could be established across both patient samples. This means that the IIQ measures the same concept(s) across both samples (Vandenberg & Lance, 2000), which is necessary to compare mean scores and correlations with psychological and physical functioning across groups. For more information about the analyses of the measurement invariance, readers can contact the corresponding author.

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298 difference testing (Brown, 2015), had significantly worse fit than the four-factor model, further
299 testifying to the distinctiveness of the illness identity states. Table 2 presents all standardized factor
300 loadings of the final four-factor solution.

301 *Reliability, correlations, and means of the IIQ*

302 Cronbach's alphas for CHD and MSDs, respectively, were .75/.75 for rejection, .83/.85 for
303 acceptance, .92/.91 for engulfment, and .95/.90 for enrichment. Acceptance correlated positively with
304 enrichment, but negatively with rejection and engulfment in both patient groups. Engulfment
305 correlated positively with rejection and enrichment in patients with CHD, and negatively with
306 acceptance in patients with MSDs (Table 3). All factor correlations were below .80, which points to
307 discriminant validity (Brown, 2015). Ancillary analyses demonstrated that these correlations did not
308 significantly differ across both samples.

309 ***Objective 2: Associations with Demographic and Clinical Parameters***

310 First, age correlated positively with engulfment ($r=.18$; $p=.003$), rejection ($r=.20$; $p=.001$), and
311 enrichment ($r=.15$; $p=.018$) in patients with CHD, and with rejection ($r=.23$; $p<.001$) in patients with
312 MSDs. Second, we found no significant multivariate sex effects for illness identity in both patients with
313 CHD ($F(1,268)=0.35$, $p=.847$, $\eta^2=.01$) and MSDs ($F(1,230)=1.93$, $p=.106$, $\eta^2=.03$). Third, in patients with
314 MSDs, disease duration correlated positively with acceptance ($r=.24$, $p<.001$). Fourth, we found
315 significant multivariate effects of condition for illness identity ($F(1,500)=20.02$, $p<.001$, $\eta^2=.14$).
316 Patients with MSDs scored higher on engulfment and rejection and lower on acceptance than patients
317 with CHD (See Table 4). Fifth, in patients with CHD, significant multivariate effects of disease
318 complexity were found for illness identity ($F(2,267)=2.73$, $p=.006$, $\eta^2=.04$). Patients with a complex
319 heart defect scored higher on engulfment and enrichment than patients with a simple heart defect.
320 Patients with a moderate heart defect scored higher on enrichment than patients with a simple heart
321 defect (See Table 5). Finally, in patients with MSDs, we found significant multivariate effects of
322 diagnosis for illness identity ($F(1,230)=4.62$, $p=.001$, $\eta^2=.08$). Patients with SSc scored higher on
323 engulfment and rejection, and lower on acceptance than patients with SLE (Table 5).

324 ***Objective 3: Associations with Psychological Functioning and Physical Functioning***

325 Given that age was significantly correlated with illness identity, correlations were calculated
326 controlling for age. These partial correlations are displayed in Table 3. In both patients with CHD and
327 MSDs, engulfment correlated positively with depressive and anxiety symptoms, and acceptance
328 correlated negatively with depressive and anxiety symptoms. In patients with CHD, engulfment,
329 rejection, and enrichment correlated positively with illness symptoms, but acceptance correlated
330 negatively with illness symptoms. In patients with MSDs, engulfment correlated positively with pain,
331 whereas acceptance correlated negatively with pain.

332 **Discussion**

333 The present study provides initial evidence that subscale scores on the Illness Identity
334 Questionnaire (IIQ; Oris et al., 2016) seem to represent the four intended illness identity states (i.e.,
335 engulfment, rejection, acceptance, and enrichment) in patients with CHD and MSDs. Patients'
336 responses to the IIQ were reliable in both samples and were related to psychological and physical
337 functioning as hypothesized (indicative of concurrent criterion validity).

338 ***Objective 1: Factorial validity and reliability of the IIQ***

339 In line with a recent study in youth with T1D (Oris et al., 2016), the four illness identity states
340 assessed in the IIQ could be differentiated, and scores on all four subscales proved to be reliable.
341 Hence, the present study demonstrated that subscale scores of the IIQ are valid indicators of illness
342 identity in adults with CHD and MSDs. The correlational pattern was similar across patient samples and
343 indicated that they were distinct but interrelated states (Brown, 2015). Engulfment and rejection were
344 positively interrelated, and were both negatively related to acceptance, as they both were
345 hypothesized to capture a lack of illness integration. Next, acceptance and enrichment were positively
346 interrelated, as they both capture instances of adaptive illness integration. In addition, enrichment and
347 engulfment were positively related, which might be explained by impact of the illness. When
348 individuals experience a substantial impact of chronic illness on their daily life, they may feel engulfed
349 by the illness (Beanlands et al., 2003). However, such an illness impact may also enable people to grow

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350 as a person (Helgeson et al., 2006). To enhance the self in the context of a stressor, individuals indeed
351 initiate cognitive efforts, such as construing benefits, which tend to be greater when stressors are
352 (perceived as) more severe (Taylor & Brown, 1988).

353 ***Objective 2: Associations with Demographic and Clinical Parameters***

354 No differences were found between men and women in the way they (fail to) integrate their
355 illness into their identity. Older patients scored higher on rejection in both patients samples, and on
356 engulfment and enrichment in patients with CHD. Older people tend to experience more disability,
357 combined with lower feelings of control as compared to younger people (Heijmans et al., 2004), which
358 makes the illness a potentially greater identity threat (Leventhal et al., 1999). Hence, one can respond
359 by rejecting the illness, because confrontation would be too overwhelming (Beanlands et al., 2003), or
360 one can feel engulfed by the illness, as if the illness takes over control of one's life. On the other hand,
361 this increased threat might also give rise to more enrichment, because the construction of benefits
362 might be greater when stressors are more severe (Helgeson et al., 2006). With regard to disease
363 duration, patients with MSDs were able to accept their illness more when they lived longer with the
364 disease, which is in contrast to the study in youth with T1D (Oris et al., 2016). However, other studies
365 have suggested that patients who lived longer with the illness were able to accept their illness more,
366 because they learned to cope with the illness challenges over time (Sparud-Lundin, Öhrn, & Danielson,
367 2010). Hence, these inconsistent results suggest that clinicians should realize that a longer disease
368 duration is not necessarily accompanied with more acceptance.

369 Further, mean differences in illness identity were found across patient samples. Patients with
370 MSDs scored higher on engulfment and rejection, and lower on acceptance than patients with CHD.
371 MSDs might pose larger identity threats than CHD as, for example, unemployment is more often the
372 case in MSDs than CHD (Haythornthwaite et al., 2003; Kovacs et al., 2005). Also, mean differences in
373 illness identity were found within patient samples. First, with respect to CHD, patients with simple,
374 moderate, and complex heart defects showed equal levels of rejection and acceptance, potentially
375 because most patients can successfully engage in adult responsibilities and roles (Kovacs et al., 2005).

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376 This might limit the threat to one's identity, even in the case of moderate or complex heart defects,
377 which might make it less necessary to reject the illness and facilitate acceptance. However, complex
378 heart defects were related to more engulfment and enrichment, and moderate heart defects were
379 related to more enrichment as compared to simple heart defects. Patients with simple heart defects
380 experience few, if any, physical limitations, compared to moderate and complex defects (Kovacs et al.,
381 2005). These aspects of the illness experience may play into experiencing engulfment and enrichment
382 (Beanlands et al., 2003; Helgeson et al., 2006). In sum, patients with simple, moderate, and complex
383 heart defects showed more similarities than dissimilarities on illness identity, but future research
384 should demonstrate which illness aspects play into these dissimilarities.

385 With respect to MSDs, patients with SSc scored higher on engulfment and rejection, and lower
386 on acceptance than patients with SLE. This is in line with research suggesting that the degree of physical
387 disability is greater in SSc than in other chronic rheumatic diseases, partly because skin thickening and
388 tightening limits hand and limb functioning (Haythornthwaite et al., 2003). This disability limits patients
389 in performing different daily activities, which might interfere with their identity roles, such as work
390 (Haythornthwaite et al., 2003). Hence, it may be more difficult to integrate SSc as part of one's identity.

391 ***Objective 3: Associations with Psychological and Physical Functioning***

392 By relating illness identity to psychological and physical functioning, we obtained a more
393 clinically relevant account of the four illness identity states in adults with a chronic illness. As expected,
394 engulfment was related to maladaptive psychological and physical functioning, that is, more
395 depressive and anxiety symptoms and more illness symptoms and pain (Oris et al., 2016). This might
396 be because the chronic illness interferes with other valued self-assets (e.g., social relationships and
397 work) (Luyckx, Goossens, Van Damme, & Moons, 2011). In the other direction, experiencing symptoms
398 and pain may interfere with everyday functioning and behaviors (Leventhal et al., 1999), which might
399 lead to feelings of engulfment.

400 For patients with CHD, rejection was related to more illness symptoms. Individuals might reject
401 their illness as part of their identity in order to avoid that the illness threatens their identity (Leventhal

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402 et al., 1999). Hence, when the threat is appraised as more severe, for example when patients
403 experience more symptoms, they might reject the illness more, as a defense mechanism (Mozzetta et
404 al., 2008). In line with results in adolescents and emerging adults with type 1 diabetes, rejection was
405 unrelated to depressive (and anxiety) symptoms (Oris et al., 2016). By avoiding confrontation with a
406 chronic illness, rejection might limit the emotional impact of the illness.

407 In line with previous research (Oris et al., 2016), acceptance was related to less depressive and
408 anxiety symptoms, and less illness symptoms and pain. Hence, the present findings testify to the
409 importance of integrating an illness in one's identity and retaining a coherent identity, as acceptance
410 was strongly related to adaptive functioning. Acceptance might enable patients to better cope with
411 illness challenges and might also lead to better self-care behaviors (Luyckx et al., 2010; Richardson et
412 al., 2001), which might lead to better psychological and physical functioning (Karademas et al., 2009).
413 However, in the other direction, experiencing few symptoms and pain might enhance acceptance,
414 because the illness does not interfere much with everyday functioning and behaviors (Leventhal et al.,
415 1999).

416 Finally, enrichment was related to more illness symptoms in patients with CHD, as individuals
417 have to experience a substantial impact of their illness in order to be able to grow as a person
418 (Helgeson et al., 2006).

419 ***Clinical Implications***

420 Given the cross-sectional nature of our study, only some preliminary clinical implications can
421 be formulated. The concept of illness identity may provide a valuable integrative framework in clinical
422 practice to understand and recognize how patients integrate (or fail to do so) a chronic illness into
423 their identity (Zangi, Hauge, Steen, Finset, & Hagen, 2011).. Hence, acknowledging patients' core
424 identity issues might be an important first step in clinical practice, in order to help patients become
425 more aware of how their illness impacts their daily life and how they perceive themselves. To that
426 extent, the IIQ could be used to assess illness identity in clinical care. However, longitudinal studies that
427 provide information on antecedents, mechanisms, and outcomes of illness identity, are necessary to

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428 understand how illness identity is related to psychological and physical functioning. Based on such
429 longitudinal studies, more profound clinical implications may be formulated

430 ***Limitations and Suggestions for Future Research***

431 The present study is characterized by some limitations. First, the most important limitation is
432 the cross-sectional study design, which does not allow drawing conclusions on the directions of effects
433 linking illness identity and functioning. Hence, in the current study, the evidence for validity of subscale
434 scores on the IIQ is limited to concurrent criterion validity, which is a weaker form of validity than
435 predictive validity. More specifically, based on our cross-sectional data, we cannot conclude whether
436 illness identity is an antecedent or consequence of psychological and physical functioning. In other
437 words, illness identity might predict psychological and physical functioning, but psychological and
438 physical functioning might also predict the way in which individuals integrate their illness into their
439 identity (i.e., illness identity). These mutual relations need to be investigated in future longitudinal
440 research. Future research should also investigate how illness identity emerges and develops over time,
441 by focusing on younger age groups such as adolescents. Second, all measures were self-report
442 questionnaires. Although these are the most appropriate method to gather information regarding
443 internal processes such as identity, other methods (e.g., interviews or objective physical functioning)
444 should be used in future research. This will allow a more in-depth understanding of illness identity.
445 Third, future research should examine the associations between illness identity and illness perceptions
446 from the Common Sense Model (CSM; Leventhal, Meyer, & Nerenz, 1980), which are different but
447 related constructs (Benyamini, 2011; Leventhal et al., 1999). Indeed, illness perceptions are part of the
448 broader self-concept (Benyamini, 2011), but they do not explicitly capture the degree to which
449 individuals manage to integrate their illness into their identity (i.e., illness identity; Oris et al., 2016).
450 However, in order to know how a person understands his (or her) chronic illness, we do not only need
451 to understand how a person perceives the illness and its treatment (i.e., illness perceptions), but also
452 how a person views him- or herself as a person *with* an illness (i.e., illness identity; Kihlstrom &
453 Kihlstrom, 1999). In the present manuscript, we only used one illness perception, illness symptoms, as

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454 a measure of subjective physical functioning in patients with CHD (Leventhal et al., 1980), but future
455 research should examine the relationship between illness perceptions and illness identity more in
456 depth. Fourth, our sample consisted solely of Caucasian European patients from a single-center setting
457 in Belgium. Although University Hospitals Leuven are the largest in Belgium, this might reduce the
458 generalizability of our findings. Fifth, we do not claim that the four illness identity states are exhaustive.
459 Other states might fit into our framework on illness identity as well and might be added based on
460 future research. However, this is the first time that four states are investigated together within an
461 integrative identity framework. Finally, because of different study designs, different measures of
462 physical functioning were used in both patient samples. Preferably, similar measures should be used
463 in future research to increase comparability of the results.

464 **Conclusion**

465 In sum, the scores of the IIQ are valid and reliable to capture four different ways of integrating an
466 illness into one's identity in adults with a chronic illness. Further, as expected, engulfment and
467 rejection capture rather maladaptive illness identities, whereas acceptance and enrichment are more
468 adaptive ways of illness integration. Hence, these findings demonstrate the need of differentiating
469 among these four illness identity states in adults with a chronic illness.

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648 Table 1

649 *Demographic and Clinical Characteristics of Patients with CHD and MSDs*

Variables	CHD	MSDs
Educational level (<i>n</i> =274/ <i>n</i> =240)		
University degree	52 (19.0)	25 (10.4)
University college degree	80 (29.2)	58 (24.2)
High school degree	131 (47.8)	126 (52.5)
Less than high school degree	11 (4.0)	31 (12.9)
Work situation (<i>n</i> =275/ <i>n</i> =241)		
Working fulltime	174 (63.3)	47 (19.5)
Working part-time	47 (17.1)	39 (16.2)
Disability/government financial assistance	24 (8.7)	55 (22.7)
Retired	10 (3.6)	69 (28.6)
Homemaker	8 (2.9)	/
Seeking for a job or unemployed	7 (2.5)	6 (2.5)
Other	5 (1.8)	25 (10.4)
Relationship (<i>n</i> =275/ <i>n</i> =241)		
Married/remarried	127 (46.2)	161 (66.8)
Unmarried/never married	77 (28.0)	19 (7.9)
Living with a partner	58 (21.1)	26 (10.8)
Seperated/divorced	12 (4.4)	21 (8.7)
Widowed	1 (0.4)	12 (5.00)
Other	/	2 (0.8)

650 *Note.* Data are presented as numbers and percentages (within parentheses).

651

Illness Identity in Chronic Illness

652 Table 2

653 *Standardized factor loadings of the Illness Identity Questionnaire*

	EFA Sample 1				CFA
	1	2	3	4	Sample 2
Engulfment items					
18. My illness limits me in many things that are important to me.	.86				.71
17. My illness prevents me from doing what I would really like to do.	.84				.64
15. My illness completely consumes me.	.82				.79
16. It seems as if everything I do, is influenced by my illness.	.79				.82
14. My illness influences all my thoughts and feelings.	.75				.80
11. My illness dominates my life.	.75				.77
13. I am preoccupied with my illness.	.72				.67
12. My illness has a strong impact on how I see myself.	.70				.72
Rejection items					
5. I just avoid thinking about my illness.		.74			.66
4. I never talk to others about my illness.		.68			.53
3. I hate being talked to about my illness.		.68			.73
2. I'd rather not think of my illness.		.53			.57
1. I refuse to see my illness as part of myself.		.41			.57
Acceptance items					
6. My illness simply belongs to me as a person.			.88		.54
7. My illness is part of who I am.			.79		.57
9. I am able to place my illness in my life.			.72		.89
8. I accept being a person with a illness.			.61		.78
10. I have learned to accept the limitations imposed by my illness.			.47		.68
Enrichment items					
23. Because of my illness, I have learned a lot about myself.				.90	.83
20. Because of my illness, I know what I want out of life.				.89	.68
21. Because of my illness, I have become a stronger person.				.87	.80
22. Because of my illness, I realize what is really important in life.				.85	.81
19. Because of my illness, I have grown as a person.				.83	.69
25. Because of my illness, I have learned to enjoy the moment more.				.81	.76
24. Because of my illness, I have learned to work through problems and not just give up.				.80	.65

654 *Note.* Only factor loadings exceeding $|\ .32 |$ are presented. For CFA, all factor loadings are significant
655 at $p < .001$. Illness was formulated as “heart defect” and “lupus/scleroderma” in Sample 1 and Sample
656 2, respectively.

Illness Identity in Chronic Illness

657 Table 3

658 *(Partial) Correlations Among Illness Identity and Psychological Functioning*

	1.	2.	3.	4.	5.	6.	7.
<i>Illness identity</i>							
1. Engulfment	1	.21***	-.43***	.22***	.55***	.45***	.61***
2. Rejection	.11	1	-.35***	-.01	.10	.02	.16**
3. Acceptance	-.39***	-.23**	1	.20**	-.22**	-.21***	-.26***
4. Enrichment	.11	.06	.20**	1	-.00	-.01	.22***
<i>Functioning</i>							
5. Depressive symptoms	.58***	.11	-.33***	-.10	1	.62***	.44***
6. Anxiety symptoms	.45***	.11	-.32***	-.12	.66***	1	.36***
7. Illness symptoms ^a / pain ^b	.40***	.07	-.17**	-.05	.30***	.43***	1

659 * $p < .05$. ** $p < .01$. *** $p < .001$. Correlations of patients with CHD are presented above the diagonal, correlations of patients with
 660 MSDs below the diagonal. Superscripts a and b refer to patients with CHD and MSDs, respectively. Correlations between illness
 661 identity and functioning were controlled for age.

Illness Identity in Chronic Illness

662 Table 4

663

664 *Univariate ANOVAs, Means, and F-values for Patient Sample*

Variables	Total	Patient Sample		F-value (η^2)
		CHD	MSDs	
<i>Illness identity</i>				
Engulfment	2.11 (0.96)	1.84 (0.88)	2.43 (0.95)	50.74*** (.02)
Rejection	2.74 (0.95)	2.63 (0.95)	2.88 (0.93)	8.88** (.11)
Acceptance	3.86 (0.93)	4.14 (0.81)	3.53 (0.95)	62.20*** (.09)
Enrichment	3.01 (1.08)	3.04 (1.15)	3.04 (1.16)	0.56 (.001)

665 *Note.* SD's are given within parentheses.

666 * $p < .05$; ** $p < .01$; and *** $p < .001$.

Illness Identity in Chronic Illness

667 Table 5

668 *Univariate ANOVAs, Means, and F-values for Disease Complexity (CHD) and Diagnosis (MSDs)*

Variables	Total CHD	Disease Complexity (CHD)			F-value (η^2)	Total MSD	Diagnosis		F-value (η^2)
		Simple	Moderate	Complex			SLE	SSc	
<i>Illness identity</i>									
Engulfment	1.85 (0.88)	1.70 (0.83) ^a	1.86 (0.89) ^{a, b}	2.19 (0.92) ^b	3.61* (.03)	2.43 (0.95)	2.25 (0.90)	2.63 (0.98)	9.57** (.04)
Rejection	2.63 (0.95)	2.75 (0.96)	2.54 (0.94)	2.69 (0.94)	1.53 (.01)	2.88 (0.93)	2.73 (0.99)	3.05 (0.83)	6.88** (.03)
Acceptance	4.15 (0.81)	4.23 (0.67)	4.13 (0.86)	4.00 (0.94)	1.11 (.01)	3.53 (0.95)	3.67 (0.98)	3.37 (0.88)	5.63* (.02)
Enrichment	3.04 (1.16)	2.76 (1.17) ^a	3.14 (1.13) ^b	3.38 (1.12) ^b	4.75** (.03)	2.97 (0.97)	3.05 (1.03)	2.89 (0.90)	1.49 (.01)

669 *Note.* SD's are given within parentheses. For disease complexity, means sharing a
 670 common superscript are not statistically different at $p < .05$ according to the Tukey HSD
 671 procedure.

672 * $p < .05$; ** $p < .01$; and *** $p < .001$.