

Illness Identity: A Novel Predictor for Healthcare Use in Adults With Congenital Heart Disease

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Background—To optimize healthcare use of adults with congenital heart disease, all important predictors of healthcare utilization should be identified. Clinical and psychological characteristics (eg, age and depression) have been found to be associated with healthcare use. However, the concept of illness identity, which assesses the degree to which congenital heart disease is integrated into one's identity, has not yet been investigated in association with healthcare use. Hence, the purpose of the study is to examine the predictive value of illness identity for healthcare use.

Methods and Results—In this ambispective analytical observational cohort study, 216 adults with congenital heart disease were included. The self-reported Illness Identity Questionnaire was used to assess illness identity states: engulfment, rejection, acceptance, and enrichment. After 1 year, self-reported healthcare use for congenital heart disease or other reasons over the past 6 months was assessed including hospitalizations; visits to general practitioner; visits to medical specialists; and emergency room visits. Binary logistic and negative binomial regression analyses were conducted, adjusting for age, sex, disease complexity, and depressive and anxious symptoms. The more profoundly the heart defect dominated one's identity (ie, engulfment), the more likely this person was to be hospitalized (odds ratio=3.76; 95% confidence interval=1.43–9.86), to visit a medical specialist (odds ratio=2.32; 95% confidence interval=1.35–4.00) or a general practitioner (odds ratio=1.78; 95% confidence interval=1.01–3.17), because of their heart defect.

Conclusions—Illness identity, more specifically engulfment, has a unique predictive value for the occurrence of healthcare encounters. This association deserves further investigation, in which the directionality of effects and the contribution of illness identity in terms of preventing inappropriate healthcare use should be determined. (*J Am Heart Assoc.* 2018;7:e008723. DOI: 10.1161/JAHA.118.008723.)

Key Words: chronic disease • congenital heart disease • depression • engulfment • illness identity • psychology and behavior

Congenital heart disease (CHD), comprising a wide spectrum of simple, moderate, and complex structural heart lesions, is the most common birth defect in newborns (9:1000 births).¹ Thanks to medical advances, 90% of children with CHD

currently survive into adulthood and the number of adults with CHD increases exponentially.^{2,3} Despite surgical repair during childhood, many adults with CHD have residual abnormalities and complications, and face psychosocial and behavioral challenges.^{4,5} Hence, these patients cannot be considered to be cured and remain regular consumers of health care.⁶ In- and outpatient healthcare use is higher in adults with CHD as compared with the general population.^{7–10} For instance, patients with moderate-to-complex lesions were about 4 times more likely than their matched controls to have >20 visits to a general practitioner in a 3-year period.⁸ Moreover, the absolute number of hospitalizations, charges, and visits to the emergency room will continue to increase, because of the growing and aging population of adults with CHD.^{11–13} For example, the absolute number of hospitalizations in this population increases by 4% annually.¹² Hence, the expected increase of healthcare use in the near future in adults with CHD is alarming.

To be able to influence the increase in demands and expenditures, modifiable predictors of healthcare use should be determined.¹⁴ Demographic (eg, age),¹⁵ clinical (eg, disease complexity),^{9,15} and psychological characteristics

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Accompanying Tables S1 and S2 are available at <http://jaha.ahajournals.org/content/7/11/e008723/DC1/embed/inline-supplementary-material-1.pdf>

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Clinical Perspective

What Is New?

- This is the first study that has investigated the predictive value of all domains of illness identity on the use of healthcare services.
- Our results showed that patients whose illness dominated their identity and daily life (ie, engulfment) were more likely to visit healthcare services because of their heart disease.

What Are the Clinical Implications?

- If future studies show that illness identity influences healthcare use, illness identity could be taken into account by health professionals while optimizing healthcare use.
- Alternatively, if future studies show that the direction of the association is the other way around (ie, healthcare use influencing illness identity), the consequences for the patient's illness identity should be kept in mind when patients consume health care.

(eg, depression, anxiety, type D personality)¹⁶ have been shown to be predictors of healthcare use in adults with CHD. Another particularly relevant concept in this regard could be “illness identity,” which is the degree to which a chronic health condition or illness, such as CHD, is integrated into one's identity.^{17,18} Identity can be defined as the degree to which an individual integrates different self-assets into a coherent sense of self, which guides choices and values in daily life.¹⁹ Patients with a chronic illness need to integrate their illness into their identity in order to achieve such a coherent sense of self.^{17,20}

Illness identity generally comprises 4 different states: engulfment, rejection, acceptance, and enrichment.¹⁸ Engulfment captures the degree to which the illness dominates one's identity and daily life. High engulfment scores are observed in patients who completely define themselves in terms of their illness.²¹ Rejection refers to the degree to which the illness is rejected as part of the patient's identity and is seen as a threat or as unacceptable to the self.^{18,22} Patients with high rejection scores tend to neglect their illness, resulting in suboptimal self-management and adherence.^{18,23} These former 2 states represent less adaptive forms of illness integration in one's identity. Next, acceptance can be defined as the degree to which patients accept their illness as part of their identity, beside other social roles and without being overwhelmed.^{18,21,22} Finally, enrichment refers to the degree to which a patient's illness results in positive life changes, enriches a patient's sense of self, and enables one to grow as a person.^{18,24} These latter 2 states represent more adaptive forms of illness integration in one's identity.

To date, no study has investigated the association between these 4 illness identity states and healthcare use. However, illness identity may partly explain individual variation in healthcare use because, for instance, patients who feel engulfed by their illness and completely define themselves in terms of their illness may be more inclined to turn to healthcare professionals when experiencing certain problems or bodily sensations. Hence, the current study aimed to explore the predictive value of illness identity on healthcare use in adults with CHD, above and beyond known demographic, clinical, and psychological predictors. More specifically, we explored (1) the association between illness identity and the occurrence of healthcare encounters, adjusted for age, sex, disease complexity, depressive and anxious symptoms; and (2) the association between illness identity and the number of visits at a healthcare service, adjusted for the same set of confounders.

Methods

The data, analytic methods, and study materials could be made available on request to other researchers for purposes of reproducing the results or replicating the procedure.

Participants and Data Collection Procedure

The present study was part of the Belgian branch of an international study, APPROACH-IS (Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease—International Study), which included >4000 adults with CHD from 15 countries around the globe.^{25,26} The rationale, design, and methods of APPROACH-IS have been detailed elsewhere.²⁵

Whereas APPROACH-IS was a cross-sectional study, the Belgian branch of this project comprised a longitudinal 3-wave cohort design with 1-year intervals (T_{2013} ; T_{2014} ; and T_{2015}). A diagram of the recruitment process and response rates of the Belgian branch can be found in Figure 1. For the present study, we used data collected at the last 2 measurement waves (ie, T_{2014} and T_{2015}). Since we needed full data for the analysis technique, only patients who participated at both T_{2014} and T_{2015} were included ($n=216$).

Inclusion criteria for the Belgian branch were (1) diagnosis of CHD, according to the definition of Mitchell (1971)²⁷; (2) patients were born before 1991; (3) diagnosis was established before the age of 10 years (ie, before adolescence to warrant sufficient experience of living with CHD); (4) continued follow-up at the University Hospitals Leuven; (5) Dutch-speaking; and (6) demonstrating physical, cognitive, and language proficiency to complete self-report questionnaires. Exclusion criteria were (1) prior heart transplantation; and (2) isolated pulmonary hypertension.²⁵ Patients were randomly selected from the database of congenital cardiology of the University

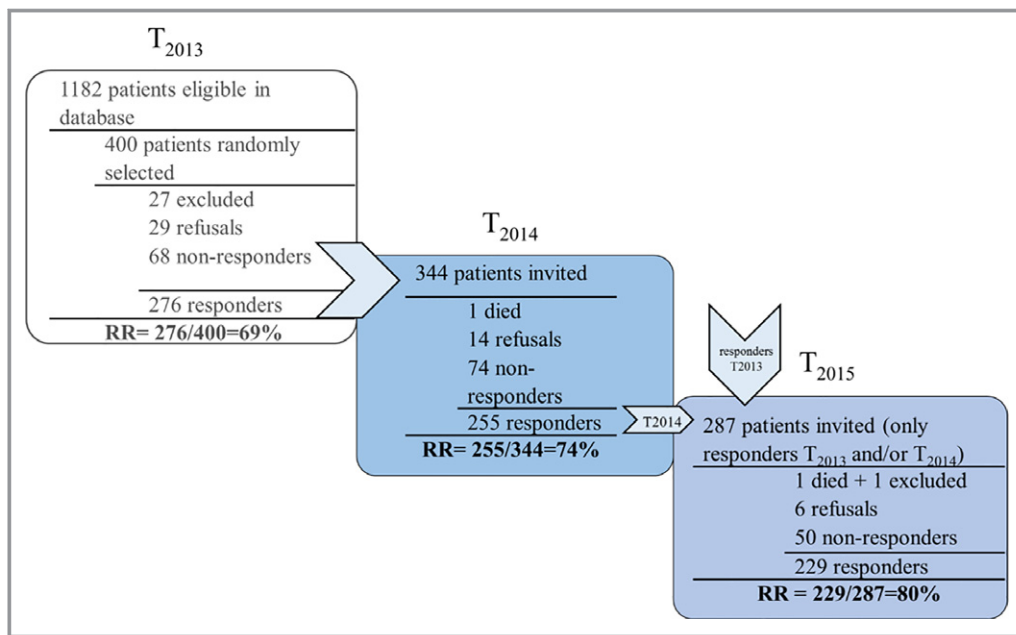


Figure 1. Diagram of the recruitment process and response rates of the Belgian branch of APPROACH-IS (Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease—International Study). RR indicates response rate.

Hospitals Leuven, a large-volume university hospital in Belgium. Eligible patients were asked to complete a set of self-reported questionnaires. A modified Dillman approach, as described earlier, was used to increase the response rate.^{28,29} Study approval was given by the institutional review board of the University Hospitals Leuven. Informed consent was obtained from each patient and procedures were in accordance with the declaration of Helsinki.³⁰ The study protocol was registered at ClinicalTrials.gov: NCT02150603. Data collection for T₂₀₁₄ and T₂₀₁₅ ran from September 2014 to March 2016.

Demographic and clinical characteristics at T₂₀₁₄ of participants included in the present study are presented in Table. Age ranged from 23 to 79 years (median=35 years; Q1=29 years; Q3=45 years) and 49.5% of patients were men. Disease complexity was categorized according to the classification of Task Force 1 of the 32nd Bethesda conference, as simple (33.8%), moderate (53.7%), or complex (12.5%).³¹

Variables and Measurement

Demographic information, disease-related information, illness identity scores, and depressive and anxiety symptoms were obtained at T₂₀₁₄, while data on healthcare use were obtained at T₂₀₁₅.

Demographic and clinical information

Demographic variables were collected through self-report and clinical variables were derived from medical records.

Illness identity

Illness identity was measured using the Illness Identity Questionnaire (IIQ). This is a self-report measure developed by Oris et al, which has been initially used and validated in adolescents and young adults with type 1 diabetes mellitus.¹⁸ Patients were asked to indicate how much they agreed with 25 statements, using a 5-point Likert scale ranging from 1 (ie, *strongly disagree*) to 5 (ie, *strongly agree*).¹⁸ The IIQ consists of a 5-item rejection scale, 7-item enrichment scale, 5-item acceptance scale, and 8-item engulfment scale. Sample items for the different subscales are, respectively, “I just avoid thinking about my illness,” “Because of my illness, I have become a stronger person,” “I am able to place my illness in my life,” and “My illness completely consumes me.” A mean score was calculated per subscale. A prior study, performed on data from T₂₀₁₃ of the Belgian branch of APPROACH-IS, demonstrated that the IIQ is valid and reliable to be used in adults with CHD.³² More specifically, exploratory and confirmatory factor analysis indicated that IIQ subscale scores could differentiate among the 4 intended illness identity states in patients with CHD and multisystem connective tissue disorders (ie, factorial validity). In those samples, patients’ responses to the IIQ were related to psychological and physical functioning (ie, concurrent criterion validity). In the present study, Cronbach α values were 0.76 for rejection, 0.81 for acceptance, 0.92 for engulfment, and 0.95 for enrichment.

Table. Demographic and Clinical Characteristics of Adults With Congenital Heart Disease at T₂₀₁₄ (n=216)

Characteristics	n (%)
Men	107 (49.5)
Median age (in y)	35 (Q1=29; Q3=45)
Highest level of education	
Less than high school	9 (4.2)
High school	97 (45.3)
College degree	65 (30.4)
University degree	43 (20.1)
Employment status	
Full-time paid work	126 (58.3)
Part-time paid work	46 (21.3)
Homemaker	6 (2.8)
Job seeking	2 (0.9)
Unemployed	3 (1.4)
Disability/government financial assistance	22 (10.2)
Retired	9 (4.2)
Other	2 (0.9)
Disease complexity, Task Force 1 ³¹	
Simple	73 (33.8)
Moderate	116 (53.7)
Complex	27 (12.5)

Depressive and anxiety symptoms

Depressive and anxiety symptoms (ie, psychological distress) were measured using the Hospital Anxiety and Depression Scale.^{33,34} This scale is a 14-item questionnaire on a 4-point Likert scale with values ranging from 0 to 3. The highest achievable overall Hospital Anxiety and Depression Scale score is 53 and high scores indicate more psychological distress. A sample item is “I still enjoy the things I used to enjoy.” A general psychological distress score was used, instead of using 2 subscores for depression and anxiety, because the Hospital Anxiety and Depression Scale was found to be more accurate when screening psychological distress.³⁵

Healthcare use

To measure healthcare use, we devised a survey developed for the purpose of this study, partly based on existing literature,^{36,37} comprising healthcare services particularly relevant for patients with CHD. Participants completed the survey form, which consisted of 8 questions about healthcare use over the past 6 months. A recall time frame of 6 months was chosen to reduce under- and overreporting and thus to increase the accuracy of the results.³⁷ More specifically, participants were asked to indicate how many times they

were hospitalized, and have visited a medical specialist, emergency room, and general practitioner, for their heart disease and for other reasons. A sample question is “How many times in the past 6 months were you hospitalized due to your heart disease?”.

Statistical analyses

Patient characteristics and healthcare use were presented as median and interquartile ranges for continuous variables and as frequency and percentage for categorical variables.

First, associations between the occurrence of healthcare encounters (yes/no) and illness identity were computed using univariate binary logistic regression analysis. Afterwards, 8 multivariable binary logistic regression analyses, with adjustments for potential confounders (ie, age, sex, disease complexity, and depressive and anxiety symptoms) were run separately for all the different healthcare services used (ie, hospitalization(s) and visit(s) to general practitioner, medical specialist, or emergency room, both related and unrelated to CHD). These results are presented as odds ratios and 95% confidence intervals (95% CI). Second, the associations between the number of visits to a particular healthcare service and illness identity were first measured using univariate negative binomial regression analyses. In these analyses, solely patients who used the respective service at least once were included. The number of hospitalizations and visits to an emergency room could not be analyzed because of small event rates (ie, 2.8%–11%). Indeed, only analyses about visits to general practitioners and medical specialists were performed. A negative binomial model was preferred to a Poisson model, because the former was more appropriate given that the data were overdispersed. Afterwards, 4 multivariable negative binomial regression analyses were run, adjusted for the abovementioned set of confounders. The results are presented as visit rate ratios and 95% CI.

There was no multicollinearity among the predictors. *P* values were based on 2-sided hypotheses and compared with a significance level of 5%. Statistical analyses were performed using the statistical package SPSS version 24 (Armonk, NY: IBM Corp).

Results

Description of Healthcare Use

A description of the healthcare use is given in Figure 2. For their heart defect, 15 patients (7.1%) required hospital admission, 109 patients (50.9%) went to a medical specialist, 6 (2.8%) patients went to the emergency room, and 54 (25.7%) patients went to a general practitioner (GP). For other reasons than their heart defect, 23 (11.0%) patients were hospitalized, 62 (29.9%) patients went to see a medical

specialist, 17 (8.0%) patients went to the emergency room, and 141 (67.1%) patients went to the GP at least once.

Illness Identity as Predictor of Healthcare Use

Illness identity and the occurrence of healthcare encounters

Univariate binary logistic regression analyses showed that patients who had not accepted their illness as part of their identity (ie, low acceptance), who were overwhelmed by their illness (ie, high engulfment), and whose illness had enriched the patient’s identity (ie, high enrichment) at T₂₀₁₄ were more likely to use health care at T₂₀₁₅, both for their heart defect and for other reasons (Table S1).

When adjusted for age, sex, disease complexity, and depressive and anxiety symptoms, multivariable analyses revealed that patients who felt engulfed by the heart defect at T₂₀₁₄ were more likely to be hospitalized (odds ratio 3.76; 95% CI, 1.43–9.86), to have a visit to a medical specialist (odds ratio 2.32; 95% CI, 1.35–4.00), and a GP (odds ratio 1.78; 95% CI, 1.01–3.17) at T₂₀₁₅, related to their heart condition (Figure 3).

Illness identity and the number of visits to GP and medical specialist

More than one quarter of the patients reported visits to a GP or medical specialist. Hence, for these outcomes, the

association between illness identity and the number of visits could be investigated. Univariate negative binomial regression analyses, which included participants who used a particular healthcare service at least once, showed that rejection, engulfment, and enrichment measured at T₂₀₁₄ were associated with an increased number of visits to a GP at T₂₀₁₅, both related and unrelated to CHD (Table S2).

When adjusting for age, sex, disease complexity, and depressive and anxiety symptoms, associations between illness identity and healthcare use were no longer found to be significant (Figure 4).

Discussion

In the current study, we explored whether illness identity was a predictor for future healthcare use in adults with CHD. We found that the level of engulfment predicted the occurrence of hospitalizations, visits to medical specialists, and visits to GPs, for medical reasons related to CHD, when adjusted for potential confounders. Furthermore, the univariate associations of rejection, engulfment, and enrichment with the number of visits at a GP were no longer significant when adjusted for the confounding factors.

The findings of the present study indicate that illness identity has a unique contribution, above and beyond known factors, when predicting the occurrence of a visit to a healthcare service, related to the heart disease. A potential

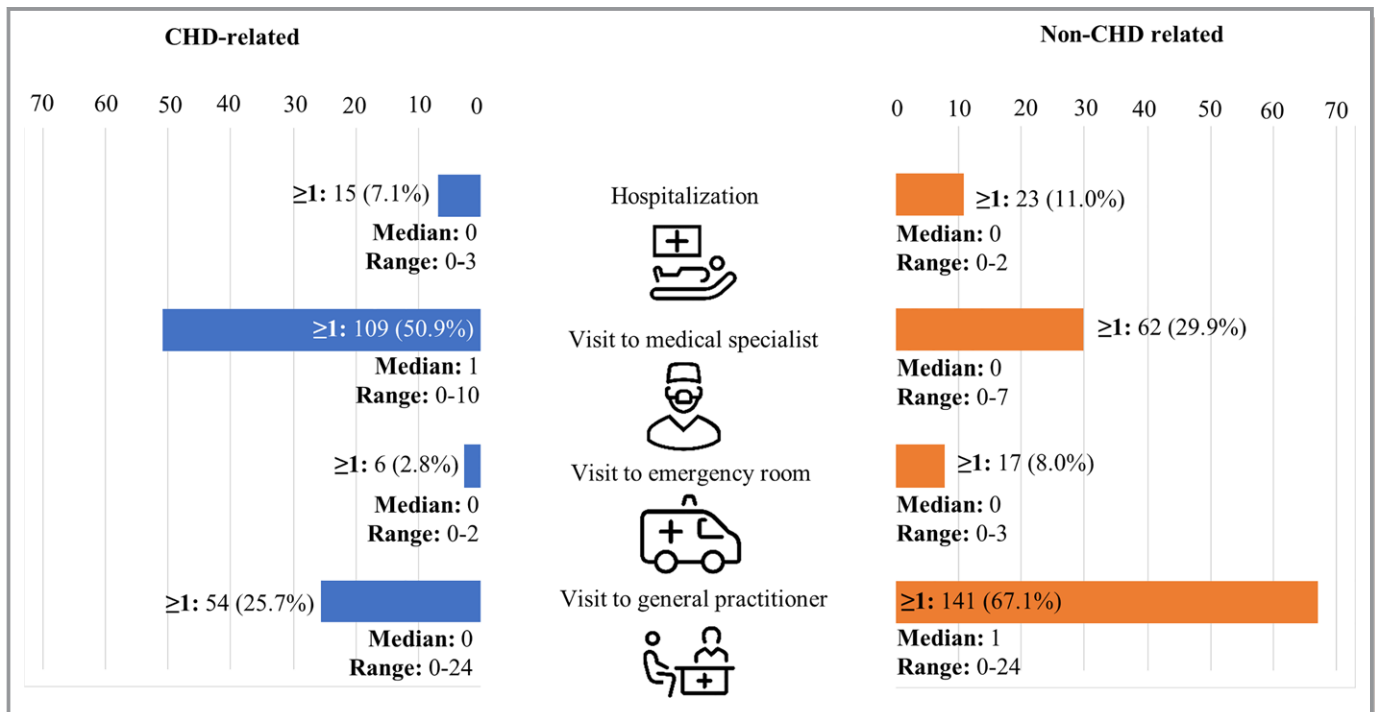


Figure 2. Description of CHD-related and non-CHD related healthcare use at T₂₀₁₅ (n=210). CHD indicates congenital heart disease. The icons were created by Delwar Hossain from the Noun Project.

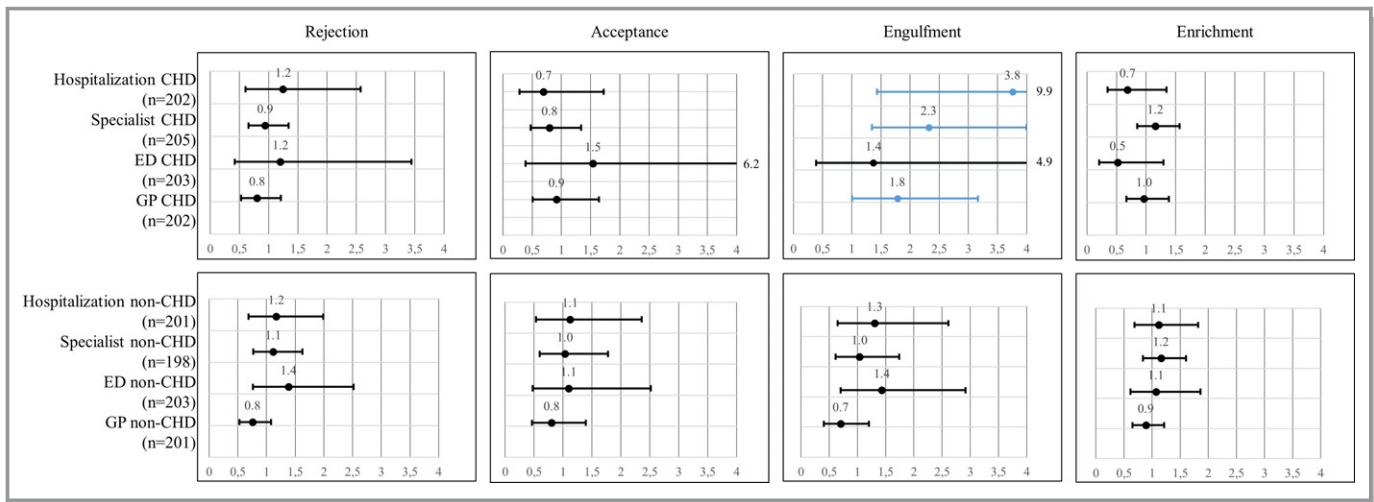


Figure 3. Association between illness identity and the occurrence of healthcare encounters (yes/no). Binary logistic regression, adjusted for age, sex, disease complexity, and depressive and anxiety symptoms. Forest plots with odds ratios and 95% confidence intervals. CHD indicates congenital heart disease; ED, emergency room; GP, general practitioner.

explanation for this association could be that patients who are overwhelmed by their condition have a lower threshold to seek care. Alternatively, this association may be bidirectional, reflecting that consumers of healthcare services could be overwhelmed by their defect more easily, because they are confronted with the downside of the condition. The role of engulfment with respect to healthcare use has only been described in previous research in a specific population of patients with psychiatric disorders.^{38,39} One of these studies showed that hospitalization is a threat to the patients viewing themselves as competent and can lead to an identity crisis.³⁹ This study suggested that healthcare use might lead to engulfment and not the other way around. Since patients with

psychiatric disorders and adults with CHD are very different patient populations and have different healthcare utilization patterns, direct comparisons are not possible and more research about the directionality of effects is needed.

This was the first investigation on the predictive value of illness identity toward healthcare utilization. Several univariate associations have been found, which were no longer significant when adjusting for confounding factors. This indicates that only the level of engulfment is associated with the occurrence of healthcare encounters for the heart defect. However, it is also possible that a more complex underlying mechanism is present. Indeed, a prior study has shown that patients who felt engulfed by their condition reported more

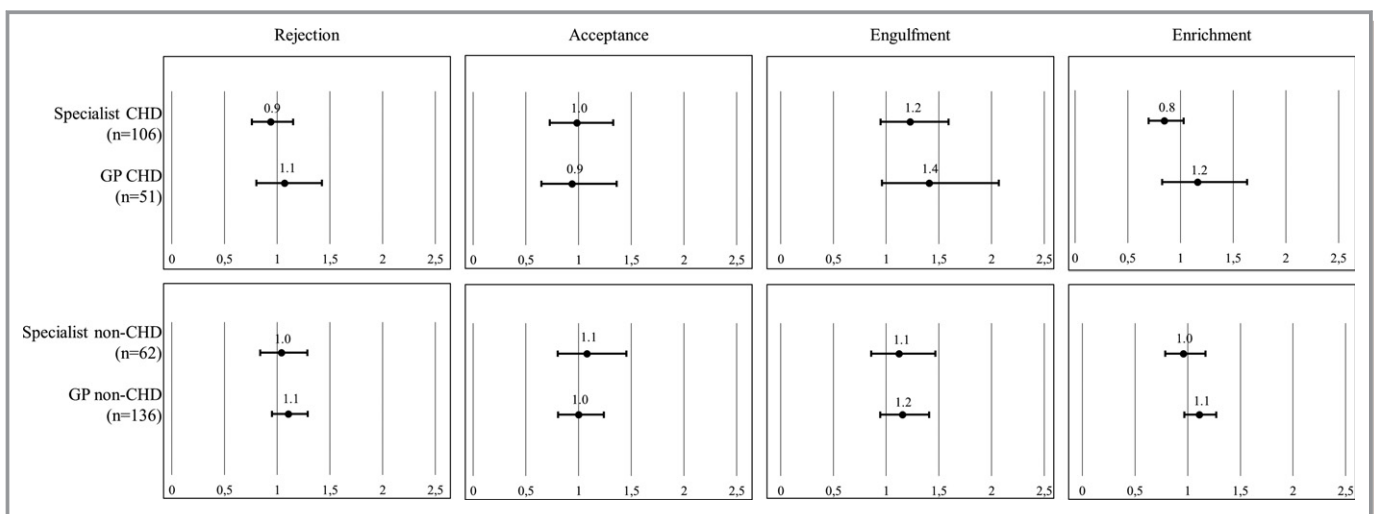


Figure 4. Association between illness identity and the amount of healthcare use. Negative binomial regression, adjusted for age, sex, disease complexity, and depressive and anxiety symptoms. Forest plots with visit rate ratios and 95% confidence intervals. CHD indicates congenital heart disease; GP, general practitioner.

depressive and anxiety symptoms.³² Such symptoms, in turn, are risk factors for higher healthcare use in adults with CHD.^{16,40} Hence, it could be possible that depressive and anxiety symptoms (ie, psychological distress) are a mediator or an intervening mechanism of the relationship between illness identity and healthcare use, rather than merely a confounding factor. However, mediation analyses could not be done in the present study because of too small event rates and too little variation in the number of visits to a service. In addition, the mediating or moderating role of other psychological concepts related to illness identity, such as illness perceptions, should be investigated. Furthermore, illness symptoms also could be a mediator, since illness symptoms are related to illness identity¹⁸ and can cause healthcare use. Hence, in future research, the underlying mechanisms should be scrutinized with a specific focus on depressive and anxiety symptoms, illness perceptions, and illness symptoms.

Clinical Implications

Provided that subsequent studies would show that illness identity influences healthcare use, illness identity could be taken into account by healthcare practitioners as a modifiable predictor of healthcare use in adults with CHD. Therefore, our findings might improve the awareness of healthcare practitioners that psychological factors, such as illness identity, might contribute to increased healthcare use. Alternatively, if future studies show that the direction of the association is the other way around (ie, healthcare use influencing illness identity), the possible consequences for the patient's illness identity should be taken into account by healthcare practitioners when patients consume health care.

Strengths, Limitations, and Suggestions for Further Research

This is the first study investigating the association between the 4 states of illness identity and healthcare use. The strengths of the study are the large sample size, random sampling technique applied, and high response rates. In the analyses, we adjusted for confounding factors, such as age, sex, disease complexity, and depressive and anxiety symptoms. Furthermore, both CHD-related and non-CHD related healthcare use were taken into account.

However, results should be interpreted in the light of certain limitations. First, data on healthcare use over the past 6 months were gathered through self-report. Hence, the responses may be subject to recall bias or telescoping. Nonetheless, the recall time frame of 6 months is more valid than broader time frames,³⁷ and previous research in patients with inflammatory bowel disease showed that self-reported healthcare use correlated strongly with medical records,⁴¹

supporting the validity of our findings. Second, because of too small event rates and too small sample sizes, particular analyses could not be performed in the present study. Future studies should investigate these associations profoundly in longitudinal causal research in a larger sample of patients who have used healthcare services, so that all types of healthcare use could be related to illness identity. Third, the directionality of effects remains unknown. To investigate the direction of the relationships, longitudinal research with multiple measurements of all variables is needed. Indeed, in our study, healthcare use was only measured at 1 occasion (ie, T₂₀₁₅). Fourth, our sample consisted of adults from a single center in Belgium and patients with severe cognitive and/or language difficulties were excluded from the study. These 2 factors might reduce the generalizability of our findings. In addition, participation bias might have affected the results. However, no significant differences were found when comparing age and sex of participants in the present study with patients who were selected, but have not or only partly participated in this Belgian branch of APPROACH-IS. Furthermore, a recent study on data of the Swedish branch of APPROACH-IS showed that differences in demographic, clinical, and health status characteristics between participants and nonparticipants were small.⁴² Fifth, the present study aimed to explore the potential of illness identity as a predictor for healthcare use, and has already corrected for a confounding factor. However, an in-depth investigation of the role of illness identity, beyond concepts such as personality, illness perceptions, and other psychological concepts, is yet to be undertaken. Furthermore, as we have only adjusted for the anatomic disease complexity of the patients, future studies should also include other clinical factors, such as cardiac symptoms, in order to correct for the true severity status of the patients. Finally, while interpreting the results, it should be kept in mind that a fairly large amount of analyses were performed, also on smaller data sets.

Conclusion

Engulfment was positively associated with having at least 1 hospitalization, a visit to the medical specialist, and the GP for CHD. This study indicated that illness identity, and more specifically the level of engulfment, is a novel predictor for healthcare use, above and beyond sex, age, disease complexity, and depression and anxiety. If the role of illness identity can be confirmed in future research, it might be a target for intervention to prevent inappropriate healthcare use.

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Disclosures

None.

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SUPPLEMENTAL MATERIAL

Table S1. Univariate analyses: association between illness identity and the occurrence of healthcare encounters (yes/no).

Predictors	Hospitalization for CHD related issues	Hospitalization for non-CHD related issues	Visit specialist for CHD related issues	Visit specialist for non-CHD related issues	Visit emergency room for CHD related issues	Visit emergency room for non-CHD related issues	Visit general practitioner for CHD related issues	Visit general practitioner for non-CHD related issues
Rejection	1.43 (0.84-2.44)	1.26 (0.81-1.95)	1.20 (0.91-1.59)	1.00 (0.73-1.37)	1.07 (0.44-2.42)	1.38 (0.84-2.30)	1.15 (0.83-1.58)	0.81 (0.60-1.08)
Acceptance	0.34 (0.17-0.66)	0.81 (0.47-1.48)	0.62 (0.41-0.91)	0.78 (0.52-1.17)	0.79 (0.31-2.58)	0.87 (0.47-1.77)	0.82 (0.54-1.25)	0.90 (0.58-1.37)
Engulfment	3.26 (1.82-6.21)	1.69 (1.03-2.76)	2.73 (1.83-4.22)	1.30 (0.90-1.88)	1.46 (0.54-3.36)	1.52 (0.86-2.62)	2.01 (1.37-3.00)	0.90 (0.63-1.29)
Enrichment	0.96 (0.60-1.55)	1.22 (0.83-1.85)	1.33 (1.04-1.72)	1.10 (0.84-1.45)	0.75 (0.36-1.56)	1.23 (0.79-1.99)	1.20 (0.91-1.60)	0.89 (0.68-1.16)
Age	1.02 (0.98-1.06)	1.02 (0.99-1.06)	1.04 (1.01-1.06)	1.00 (0.97-1.02)	1.00 (0.93-1.07)	1.02 (0.98-1.06)	1.05 (1.02-1.07)	1.00 (0.98-1.03)
Sex	0.86 (0.29-2.48)	0.51 (0.20-1.22)	0.89 (0.52-1.53)	1.61 (0.89-2.96)	1.02 (0.18-5.62)	0.53 (0.18-1.45)	1.10 (0.59-2.06)	1.66 (0.93-2.99)
Complexity	1.03 (0.45-2.30)	0.90 (0.45-1.73)	1.16 (0.77-1.77)	0.85 (0.53-1.34)	3.79 (1.07-15.68)	1.10 (0.50-2.34)	1.67 (1.03-2.74)	1.14 (0.73-1.79)
Depressive and anxiety symptoms	1.08 (1.01-1.16)	1.07 (1.01-1.14)	1.07 (1.02-1.12)	1.08 (1.03-1.13)	1.06 (0.96-1.18)	1.03 (0.96-1.11)	1.07 (1.02-1.12)	1.04 (0.99-1.09)

Binary logistic regression, adjusted for age, sex, and disease complexity. Odds ratios and 95% confidence intervals are displayed. Statistically significant ($p < 0.05$) odds ratio's (OR) are in bold. CHD=congenital heart disease

Table S2. Univariate analyses: association between illness identity and amount of healthcare use.

<u>Predictors</u>	Visit general practitioner for CHD related issues	Visit general practitioner for non-CHD related issues	Visit specialist for CHD related issues	Visit specialist for non-CHD related issues
Rejection	1.09 (0.84-1.42)	1.17 (1.02-1.35)	1.02 (0.87-1.19)	0.98 (0.82-1.17)
Acceptance	1.07 (0.79-1.43)	0.94 (0.78-1.15)	0.86 (0.70-1.08)	1.00 (0.82-1.24)
Engulfment	1.39 (1.02-1.92)	1.37 (1.17-1.61)	1.18 (0.98-1.40)	1.08 (0.90-1.28)
Enrichment	1.35 (1.07-1.71)	1.20 (1.06-1.35)	0.90 (0.77-1.06)	1.03 (0.88-1.21)
Age	1.02(1.00-1.04)	1.02 (1.01-1.03)	1.00 (0.99-1.01)	1.00 (0.99-1.02)
Sex	1.35 (0.83-2.22)	1.33 (1.00-1.76)	0.90 (0.66-1.22)	1.26 (0.87-1.85)
Complexity	0.69 (0.47-1.01)	1.00 (0.80-1.25)	1.10 (0.86-1.39)	1.22 (0.87-1.73)
Depressive and anxiety symptoms	1.06 (0.99-1.14)	1.05 (1.03-1.08)	1.04 (1.01-1.07)	1.06 (1.01-1.11)

Negative binomial regression, adjusted for age, sex, and disease complexity. Visit rate ratios and 95% confidence intervals are displayed.

Statistically significant ($p < 0.05$) visit rate ratios are in bold. CHD=congenital heart disease