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Illness perceptions in adult congenital heart disease:

A multi-center international study

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Abstract

Background. Illness perceptions are cognitive frameworks that patients construct to make sense of their illness. Although the importance of these perceptions has been demonstrated in other chronic illness populations, few studies have focused on the illness perceptions of adults with congenital heart disease (CHD). This study examined (1) inter-country variation in illness perceptions, (2) associations between patient characteristics and illness perceptions, and (3) associations between illness perceptions and patient-reported outcomes.

Methods. Our sample, taken from APPROACH-IS, consisted of 3,258 adults with CHD from 15 different countries. Patients completed questionnaires on illness perceptions and patient-reported outcomes (i.e., quality of life, perceived health status, and symptoms of depression and anxiety). Patient characteristics included sex, age, marital status, educational level, employment status, CHD complexity, functional class, and ethnicity. Linear mixed models were applied.

Results. The inter-country variation in illness perceptions was generally small, yet patients from different countries differed in the extent to which they perceived their illness as chronic and worried about their illness. Patient characteristics that were linked to illness perceptions were sex, age, employment status, CHD complexity, functional class, and ethnicity. Higher scores on consequences, identity, and emotional representation, as well as lower scores on illness coherence and personal and treatment control, were associated with poorer patient-reported outcomes.

Conclusions. This study emphasizes that, in order to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity such as the complexity of the heart defect, but also on subjective illness experiences.

Keywords: heart defects, congenital; illness perceptions; international cooperation, multilevel analysis; psychosocial care.

1. Introduction

Over the past decades, congenital heart disease (CHD) has been transformed from a condition with lethal consequences into a manageable chronic condition [1]. Although adult patients often have to deal with various challenges [2,3], prior research has typically found few differences in quality of life and emotional functioning between patients and healthy controls, except for a reduced quality of life in the physical domain [4-7]. At the same time, large inter-individual differences have been observed among patients [8]. To understand why some patients show poor functioning whereas others display signs of resilience, it is important that research identifies modifiable determinants through which patients' functioning can be improved. A potentially important determinant, which has not received much attention to date in this population, is patients' illness perceptions. Illness perceptions are cognitive frameworks which patients construct to make sense of their illness and which may guide behavior directed at managing the illness [9-12]. Patients' perceptions of their illness are known to vary widely, even among patients with similar illnesses [13].

Little is known about the ways in which illness perceptions are formed but they are likely to be drawn from multiple sources of information, both at the level of the patient and the larger context [11-15]. With regard to patient characteristics, female patients have been found to perceive their illness as more chronic, to report more symptoms, and to feel less in control of their illness [16-17]. However, overall, limited knowledge exists about which patient characteristics are associated with illness perceptions in adults with CHD. With regard to the larger context, researchers have emphasized the role of family, peers, health-care providers, and one's culture [12,13,15]. Although previous studies have described cross-cultural differences in illness perceptions within certain chronic illness populations [18,19], quantitative research systematically comparing patients' illness perceptions across different cultures or countries, using a uniform methodology, is virtually non-existent. In addition, it remains unclear how potential differences could be understood, as inter-country variation in illness perceptions could be explained by both cultural [13,14] and health care system factors [2,20].

A large body of literature has shown that patients' illness perceptions are related to important patient-reported outcomes such as depressive symptoms and treatment adherence among adults with diverse health conditions [9-12]. Illness perceptions were even found to predict all-cause mortality among patients with renal failure, after controlling for clinical factors and depression [21]. In many cases, illness perceptions are associated more strongly with patient-reported outcomes than objective measures of illness severity [22]. To date, only three studies have looked at the illness perceptions of adults with CHD. These studies have found important associations with patients' quality of life [23,24], depressive symptoms [24], and health care use [25]. Although these studies have provided important insights, findings from single-center and regional multi-center studies need to be replicated in a large and diverse international sample, with appropriate control for demographic and clinical factors.

To fill these gaps in the literature, the present study examined (a) inter-country variation in illness perceptions and the role of country-specific characteristics (i.e., overall health system performance and national culture); (b) associations between a broad range of patient characteristics and illness perceptions; and (c) associations between illness perceptions and patient-reported outcomes (i.e., quality of life, perceived health status, and symptoms of depression and anxiety).

2. Methods

2.1. Study population and procedure

The present study is part of a large international study, entitled Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS) [26,27]. APPROACH-IS is a cross-sectional study conducted in partnership with the International Society for Adult Congenital Heart Disease (ISACHD). Data was collected in 15 countries: Argentina, Australia, Belgium, Canada, France, India, Italy, Japan, Malta, Norway, Sweden, Switzerland, Taiwan, the Netherlands, and the United States of America (USA). Inclusion criteria were: (i) diagnosis of CHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that is present at birth and is actually or potentially functionally significant [28]; (ii) 18 years of age or older; (iii) diagnosis established before adolescence; (iv) continued follow-up at a CHD center or included in a

national/regional registry; and (v) the physical, cognitive, and language capacity for completing the self-report questionnaires. Patients with prior heart transplantation or primary pulmonary hypertension were excluded. Eligible patients were mailed a questionnaire package or received it in clinic during an outpatient visit. Overall, 4,028 adults with CHD were enrolled in APPROACH-IS. This study was performed according to the ethical guidelines of the 2013 Declaration of Helsinki and approved by the institutional review board of the University Hospitals Leuven and the local institutional review board of participating centers when required. All subjects provided written informed consent to participate. More detailed information on the design is available in a published methods paper [26].

2.2. Assessment

Patient characteristics. Information on sex, age, marital status, educational level, employment status, New York Heart Association (NYHA) functional class, and ethnicity was collected using a self-report questionnaire. The complexity of patients' heart defects (i.e., simple, moderate, or complex) was extracted from medical records [26].

Illness perceptions. The Brief Illness Perception Questionnaire (Brief IPQ), consisting of nine single items, was administered to assess patients' illness perceptions [29]. Items are rated from 0 to 10 and measure perceived consequences (*"How much does your illness affect your life?"*), timeline (*"How long do you think your illness will continue?"*), personal control (*"How much control do you feel you have over your illness?"*), treatment control (*"How much do you think your treatment can help your illness?"*), identity (*"How much do you experience symptoms from your illness?"*), concern (*"How concerned are you about your illness?"*), coherence (*"How well do you feel you understand your illness?"*) and emotional representations (*"How much does your illness affect you emotionally, e.g., does it make you angry, sad, upset, or depressed?"*).

Patient-reported outcomes. To assess quality of life, we administered the Satisfaction with Life Scale (SWLS) [30]. Quality of life was defined as *"the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain aspects of life important to*

them, including matters both related and unrelated to health” [31]. The SWLS comprises five statements with a response scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Cronbach’s alpha was .89. To assess perceived health status, we administered the EuroQoL-5D (EQ-5D) visual analog scale ranging from 0 (*best imaginable health state*) to 100 (*worst imaginable health state*) [32]. In addition, we administered the 12-item Short-Form Health Survey version 2 (SF-12v2) measuring eight health domains: physical functioning, role participation with physical health problems, bodily pain, general health, vitality, social functioning, role participation with emotional health problems, and mental health [33]. The SF-12 produces a Mental Component Summary (MCS) and a Physical Component Summary (PCS). Scores range from 0 to 100, with higher scores reflecting a better health status. Cronbach’s alpha was .86 for the MCS and .87 for the PCS. Finally, to assess symptoms of depression and anxiety, we administered the Hospital Anxiety and Depression Scale (HADS), which includes two seven-item subscales [34]. Subscale scores range from 0 to 21, with higher scores reflecting greater distress. Cronbach’s alpha was .82 for anxiety and .80 for depression.

Country-specific characteristics. We measured the overall health system performance for each country using the assessment system of the World Health Organization, which is based on five indicators (i.e., the overall level of population health, health inequalities within the population, the overall level of health system responsiveness, the distribution of responsiveness within the population, and the distribution of the health system's financial burden within the population) and takes into account the resources available in each country [35]. National culture was assessed using Hofstede’s six dimensions: a power distance index (higher scores reflect higher levels of acceptance that power is distributed unequally in society), individualism versus collectivism (higher scores reflect individualistic societies), masculinity versus femininity (higher scores reflect more masculine societies directed towards achievement and success), uncertainty avoidance index (higher scores reflect societies that are more rigid in beliefs and behaviors), long-term versus short-term normative orientation (higher scores are associated with thriftiness and perseverance), and indulgence versus restraint (higher

scores reflect societies that foster gratification of human drives related to enjoying life and having fun) [36]. Data on these country-specific characteristics is provided in Online Table 1.

2.3. Statistical analyses

Given that the collected data are hierarchical, we conducted multilevel analyses in IBM SPSS Statistics 23 (Armonk, NY). A two-level structure in which patients were nested within countries was assumed. We used multivariable general linear mixed models (GLMMs) to examine inter-country variation in illness perceptions, the role of country-specific characteristics, and associations among illness perceptions, patient characteristics, and patient-reported outcomes. A (pseudo) R^2 statistic referred to as R^2_{SAS} in Shtatland et al. [37] was derived from the model χ^2 . This is an approximate estimate for the percentage explained variance. Because of the large sample size, the statistical significance threshold was set to $p \leq .01$. Only patients for whom full data were available for all study variables were included in the GLMMs ($N = 3,258$ or 81%). Sample characteristics are detailed in Table 1. χ^2 -analyses and univariate analyses of variances (ANOVAs) showed that patients with and without missing information differed on several of the study variables. However, Cramér's V and Cohen's d indicated that these differences were relatively small [38].

3. Results

3.1. Inter-country variation in illness perceptions

Substantial inter-country variation was observed in patients' illness perceptions. Patients from France perceived their illness as having more consequences (3.84), while patients from Malta perceived few consequences of their illness (1.97). Regarding timeline, patients from Norway perceived their illness as being more chronic in nature (9.5), whereas patients from India perceived their illness as more acute (4.38). The lowest level of personal control was found in patients from Switzerland (5.40), while patients from Japan reported the highest levels of personal control (7.72). Patients from Japan also obtained the highest scores on treatment control (8.56), whereas patients from Taiwan obtained the lowest scores on treatment control (6.40). With regard to identity, patients from India reported the most symptoms (4.21), while patients from Malta reported the least symptoms

(2.15). The lowest level of concern was found in patients from Sweden (3.09), whereas the highest level of concern was reported by patients in Taiwan (7.61) and France (7.60). Patients in Argentina obtained the highest scores on illness coherence (8.50), while patients from Australia obtained the lowest scores (6.95). Finally, with regard to emotional representation, patients from Canada (4.42), France (4.40), and India (4.40) reported the most illness-related negative emotions, whereas patients from Switzerland experienced the least negative emotions (2.60). Figure 1 displays mean scores on all eight illness perceptions (with 95% confidence intervals) for each participating country. As shown in Table 2, country differences only explained 1% to 12% of the variation in illness perceptions above and beyond patient characteristics. Two additional GLMM analyses demonstrated that, after adjusting for patient characteristics, national culture and overall health system performance were not significantly associated with variation in illness perceptions (Online Table 2). Adding these country-specific characteristics to the model increased the explained variance by less than 1%.

3.2. Associations between patient characteristics and illness perceptions

Table 2 presents the results of the multivariate GLMM analyses. In general, patient characteristics explained 3% to 34% of the variation in illness perceptions. Men reported fewer symptoms and experienced fewer illness-related negative emotions as compared to women. Older patients perceived their illness as having more consequences, reported more symptoms, felt more concerned about their illness, but also reported a more coherent illness understanding. Patients who were unemployed, job seeking, or disabled reported more consequences, symptoms, and negative emotions as compared to patients who worked part- or fulltime. With regard to illness complexity, patients with a heart defect of greater complexity reported more consequences, symptoms, and negative emotions as compared to patients with a simple defect. In addition, patients with a heart defect of moderate or great complexity perceived their illness as being more chronic, felt more concerned, and had a stronger belief that their treatment can control the illness as compared to patients with a simple defect. Relatedly, poorer NYHA functional classes were related to more perceived consequences, symptoms, concerns and negative emotions, fewer feelings of personal and

treatment control, lower levels of illness coherence, and stronger perceptions of the illness as being chronic. Finally, patients with an Asian background reported more consequences and symptoms, and perceived their illness as being more acute as compared to patients with a White/Caucasian background. In addition, compared to patients with a White/Caucasian background, patients with a Black/African-American background reported more symptoms and patients with a Hispanic/Latino background reported stronger feelings of personal control.

3.4. Associations between illness perceptions and patient-reported outcomes

Table 3 presents the results of the multivariate GLMM analyses. In general, illness perceptions explained 16% to 27% of the variation in patient-reported outcomes. Patients who perceived their illness as having more consequences reported a poorer quality of life and health status and more depressive symptoms. Stronger perceptions of personal control were related to a better quality of life and perceived health status (findings significant for the MCS only). Patients who believed that their treatment can control their illness also reported a better quality of life and health status as well as fewer symptoms of depression and anxiety. More perceived symptoms, a less coherent illness understanding, and more negative emotions were related to a poorer quality of life and perceived health status and more symptoms of depression and anxiety. Finally, patients who felt more concerned about their illness reported a better health status (findings significant for the MCS only).

4. Discussion

The present study examined the illness perceptions of adults with CHD using data from APPROACH-IS, an international project sampling more than 4,000 patients from 15 different countries across 5 continents. Important associations were uncovered which can guide health-care professionals in identifying patients.

4.1. Study findings

First, we observed an element of inter-country variation in patients' illness perceptions. Previous – mainly qualitative – studies have described cross-cultural differences in illness perceptions within certain chronic illness populations [18,19]. More specifically, Western cultures have been found

to emphasize biomedical explanations for illness, whereas non-Western cultures typically assign a greater role to the social and moral aspects of the illness [13]. However, quantitative research systematically comparing patients' illness perceptions across countries along the eight dimensions of the IPQ is virtually non-existent. In the present study, we found that patients from India, Italy, and Malta tended to recognize the chronic nature of their illness less strongly as compared to patients from other countries such as Sweden, Switzerland, and Norway. In addition, we found that patients from France and Taiwan worried most about their illness, whereas patients from Sweden, the Netherlands, and Switzerland generally reported few concerns. These inter-country differences were obtained after controlling for patient characteristics, including ethnicity. National culture and overall health care performance were not associated with inter-country variation in illness perceptions. Future research should examine other country- or center-specific characteristics that may account for these differences across countries, such as the extent to which patients are offered psychosocial counseling and structured education during outpatient visits [13,15].

Second, sex, age, employment status, CHD complexity, NYHA functional class, and ethnicity were found to be related to patients' illness perceptions. These findings partially replicate the findings from Schoormans et al. [23], who also found patients with a more complex CHD and poorer functional class to perceive more consequences of their illness, to experience more illness-related negative emotions and less treatment control, and to show a less coherent illness understanding. Furthermore, our findings extend the general literature in which women have been found to show a greater tendency to adopt the sick role and to experience and report more somatic symptoms compared to men [16,17]. Knowledge of these patient characteristics may assist health-care providers in better understanding the perceptions that patient hold about their illness. However, these patient characteristics only explained a small proportion of the variability in illness perceptions. Future research should examine other influential factors such as patients' personality [39].

Third, substantial associations were uncovered between illness perceptions and patient-reported outcomes, thereby extending findings from previous single-center and regional multi-center

studies. In line with previous research among adults with diverse health conditions [13], including adults with CHD [23,24], perceiving the illness as having a strong impact on daily life, attributing more symptoms to the illness, and experiencing more negative emotions related to the illness, was associated with a poorer quality of life and perceived health status and more symptoms of depression and anxiety. In contrast, feeling in control of the illness, believing that the treatment can control the illness, and showing a coherent illness understanding was associated with a better quality of life and perceived health status and fewer symptoms of depression and anxiety. These associations remained significant after controlling for CHD complexity and NYHA functional class. Hence, our findings indicate that, to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity but also on subjective illness experiences [21].

4.2. Implications for clinical practice

Although researchers have stressed the importance of listening to patients' thoughts and concerns decades ago [40], they are still rarely being addressed as part of routine medical care [3]. Nonetheless, it is important that CHD care providers take time to talk to patients about their worries, the challenges they are faced with in their everyday lives, and what they feel is the best way to deal with these challenges [9,40]. This could help prevent misunderstandings between patients and health-care professionals, who often differ in their views of the illness [41]. Already in the pediatric setting, CHD care providers should help adolescents and their parents in developing adaptive illness perceptions, such as higher levels of illness coherence and personal control. The period of adolescence seems ideally suited to help shape patients' illness perceptions [45], as adolescents start developing their own personal identity and more abstract, future-oriented thoughts and concerns emerge [46,47], making them more aware of what it means to live with a chronic illness. If CHD care providers feel that patients have developed inaccurate or unrealistic illness perceptions, referral to a mental health practitioner may be advised. In other patient samples, brief psycho-educational interventions aimed at modifying patients' illness perceptions have been found to result in a better quality of life, treatment adherence, and less symptoms of depression and anxiety [42-44].

4.3. Limitations and suggestions for future research

Although the present study has important strengths, findings should be interpreted in light of certain limitations. Firstly, as a cross-sectional study, causality cannot be determined. Future longitudinal studies should assess illness perceptions and patient-reported outcomes at multiple time points, which would provide insights into their developmental interplay over time. Secondly, the present study did not examine potential mediators in the relationship between illness perceptions and patient-reported outcomes. Previous research in other chronic illness populations has found substantial associations between patients' illness perceptions and coping strategies [12]. Future research should examine the dynamic relationship among illness perceptions, coping, and patient-reported outcomes in CHD patients. Third, we were not able to verify differential item functioning, which refers to the probability that people from different countries, completing questionnaires in their own language, provide a certain response on a questionnaire [48]. However, it should be noted that the brief IPQ has previously been used in 36 countries and has been translated into 26 different languages [49]. Fourthly, some factors may compromise the generalizability of our findings. For most participating countries, data from only one center was available. However, some participating centers were national reference centers accommodating patients from all over the country. In addition, selection bias might have affected the results. Because of the in-clinic recruitment in most participating centers, it was not possible to determine response rates or compare background data from responders and non-responders. However, a recent study using the Swedish data of APPROACH-IS showed that the differences between responders and non-responders were relatively minor [50]. Finally, patients with physical or cognitive difficulties who were not capable of filling out questionnaires are not represented in this study.

4.4. Conclusion

The present study was the first to examine inter-country variation in illness perceptions, associations between patient characteristics and illness perceptions, and associations between illness perceptions and patient-reported outcomes in such a large and diverse sample of adults with CHD.

Although the inter-country variation in illness perceptions was generally small, patients from different countries differed in the extent to which they perceived their illness as chronic and worried about their illness. Patient characteristics that were linked to patients' illness perceptions were sex, age, employment status, CHD complexity, NYHA functional class, and ethnicity. After controlling for patient characteristics, substantial associations were observed between patients' illness perceptions and their quality of life, perceived health status, and symptoms of depression and anxiety. Hence, in order to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity but also on subjective illness experiences.

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Table 1.

Comparison of patients included in the present study ($N = 3,258$) and those excluded because of missing information ($N = 770$).

| | Included (%) | Excluded (%) | Chi-square (df) | p | Cramér's V |
|--|-----------------|-----------------|--------------------|--------|-----------------|
| Sex ($N = 4,012$) | | | 11.29 (1) | .001 | .05 |
| Men | 1582 (49%) | 315 (42%)* | | | |
| Women | 1676 (51%) | 439 (58%)* | | | |
| Illness complexity ($N = 4,028$) | | | 10.39 (2) | .006 | .05 |
| Simple | 806 (25%) | 234 (30%)* | | | |
| Moderate | 1607 (49%) | 350 (46%) | | | |
| Complex | 845 (26%) | 186 (24%) | | | |
| Marital status ($N = 4,008$) | | | 17.93 (3) | < .001 | .07 |
| Unmarried | 1465 (45%) | 288 (38%)* | | | |
| Married or living together | 1638 (50%) | 407 (54%) | | | |
| Divorced or widowed | 152 (5%) | 52 (7%)* | | | |
| Other | 3 (0%) | 3 (0%) | | | |
| Education level ($N = 3,989$) | | | 36.49 (3) | < .001 | .10 |
| Less than high school | 152 (5%)* | 71 (10%)* | | | |
| High school | 1383 (42%) | 332 (45%) | | | |
| College degree | 704 (22%) | 142 (19%) | | | |
| University degree | 1019 (31%) | 186 (25%)* | | | |
| Employment status ($N = 4,005$) | | | 30.01 (4) | < .001 | .09 |
| Full- or parttime work | 2089 (64%) | 465 (62%) | | | |
| Homemaker or retired | 243 (8%) | 88 (12%)* | | | |
| Job seeking/unemployed/disabled | 401 (12%) | 114 (15%) | | | |
| Student | 285 (9%) | 42 (6%)* | | | |
| Other | 240 (7%) | 38 (5%) | | | |
| NYHA functional class ($N = 3,927$) | | | 9.06 (3) | .029 | .05 |
| Class I ^a | 1729 (53%) | 380 (57%) | | | |
| Class II | 1170 (36%) | 205 (31%) | | | |
| Class III | 238 (7%) | 49 (7%) | | | |
| Class IV ^b | 121 (4%) | 35 (5%) | | | |
| Ethnicity ($N = 3,944$) | | | 36.96 (5) | < .001 | .10 |
| White/Caucasian | 2908 (74%) | 537 (78%) | | | |
| Middle-Eastern/Arabic | 40 (1%) | 12 (2%) | | | |
| Asian | 695 (21%)* | 86 (13%)* | | | |
| Black/African-American | 34 (1%) | 7 (1%) | | | |
| Hispanic/Latino | 94 (3%) | 37 (5%)* | | | |
| Other | 24 (0%) | 7 (1%) | | | |

| | Included (%) | Excluded (%) | Chi-square (df) | <i>P</i> | Cramér's <i>V</i> |
|---|-----------------|-----------------|--------------------|----------|----------------------|
| Country (<i>N</i> = 4,028) | | | 143.36 (14) | < .001 | .19 |
| Argentina | 131 (4%) | 47 (6%)* | | | |
| Australia | 118 (4%) | 14 (2%)* | | | |
| Belgium | 225 (7%) | 51 (7%) | | | |
| Canada | 422 (13%) | 101 (13%) | | | |
| France | 73 (2%) | 23 (3%) | | | |
| India | 159 (5%) | 41 (5%) | | | |
| Italy | 47 (1%) | 19 (3%) | | | |
| Japan | 224 (7%) | 33 (4%) | | | |
| Malta | 74 (2%)* | 45 (6%)* | | | |
| Norway | 154 (5%) | 20 (3%)* | | | |
| Sweden | 366 (11%) | 105 (14%) | | | |
| Switzerland | 191 (6%)* | 87 (11%)* | | | |
| Taiwan | 247 (8%)* | 3 (0%)* | | | |
| The Netherlands | 201 (6%) | 55 (7%) | | | |
| USA | 626 (19%) | 126 (16%) | | | |
| | Included | Excluded | <i>F</i> -test | <i>P</i> | Cohen's <i>d</i> |
| Age (<i>N</i> = 4,021) | 34.21 | 37.34 | 36.36 | < .001 | -.23 |
| Consequences (<i>N</i> = 3,977) | 3.24 | 2.97 | 5.47 | .019 | .09 |
| Timeline (<i>N</i> = 3,910) | 8.34 | 8.29 | 0.12 | .727 | .02 |
| Personal control (<i>N</i> = 3,937) | 6.10 | 6.20 | 0.58 | .447 | -.03 |
| Treatment control (<i>N</i> = 3,750) | 7.35 | 7.49 | 0.92 | .337 | -.05 |
| Identity (<i>N</i> = 3,938) | 3.12 | 2.85 | 5.41 | .020 | .10 |
| Concern (<i>N</i> = 3,959) | 5.05 | 4.45 | 19.26 | < .001 | .18 |
| Coherence (<i>N</i> = 3,953) | 7.90 | 8.03 | 2.04 | .153 | -.06 |
| Emotional representation (<i>N</i> = 3,961) | 3.65 | 3.29 | 7.51 | .006 | .11 |
| SWLS (<i>N</i> = 3,892) | 25.28 | 26.05 | 7.34 | .007 | -.12 |
| HADS-D (<i>N</i> = 3,995) | 3.22 | 3.25 | 0.05 | .829 | -.01 |
| HADS-A (<i>N</i> = 3,985) | 5.66 | 5.40 | 2.71 | .100 | .07 |
| PCS (<i>N</i> = 4,026) | 77.41 | 76.44 | 1.34 | < .001 | .05 |
| MCS (<i>N</i> = 4,024) | 72.09 | 72.04 | 0.01 | .946 | .00 |
| EQ-VAS (<i>N</i> = 3,961) | 77.76 | 78.30 | 0.63 | .426 | -.03 |

Note. NYHA= New York Heart Association. SWLS= Satisfaction with Life Scale; HADS-D= Hospital Anxiety and Depression Scale – Depression; HADS-A= Hospital Anxiety and Depression Scale – Anxiety; PCS= Physical Component Summary; MCS= Mental Component Summary; EQ-VAS= EuroQol 5 Dimensions-Visual Analog Scale. ^aNot limited during physical activities. ^bUnable to be physically active without experiencing discomfort. *Standardized residual >|2|.

Table 2.

Results from the GLMMs examining associations between patient characteristics and illness perceptions.

| | Consequences | Timeline | Personal control | Treatment control | Identity | Concern | Coherence | Emotional representation |
|---------------------------------|--------------|----------|---------------------|----------------------|----------|---------|-----------|-----------------------------|
| Patient characteristics | | | | | | | | |
| Sex | | | | | | | | |
| Men | -0.09 | 0.14 | -0.07 | -0.07 | -0.25** | -0.26 | -0.12 | -0.36*** |
| Women | # | # | # | # | # | # | # | # |
| Age | 0.03*** | 0.01 | 0.01 | 0.01 | 0.02*** | 0.02** | 0.02*** | 0.01 |
| Marital Status | | | | | | | | |
| Married/ living with partner | # | # | # | # | # | # | # | # |
| Unmarried | 0.24 | -0.15 | 0.05 | -0.02 | 0.12 | -0.18 | -0.12 | 0.09 |
| Divorced or widowed | -0.03 | -0.29 | -0.10 | -0.09 | 0.18 | -0.26 | -0.11 | -0.11 |
| Other | 0.73 | 2.72 | -2.57 | -2.16 | 2.12 | 1.75 | -1.74 | 1.87 |
| Educational level | | | | | | | | |
| Less than high school | -0.03 | -0.22 | -0.02 | 0.33 | 0.31 | -0.31 | -0.25 | 0.26 |
| High school | 0.01 | -0.16 | 0.07 | 0.09 | 0.21 | 0.21 | -0.22 | 0.06 |
| College degree | 0.01 | -0.15 | 0.12 | 0.05 | 0.14 | -0.10 | -0.23 | -0.07 |
| University degree | # | # | # | # | # | # | # | # |
| Employment Status | | | | | | | | |
| Part- or full-time work | # | # | # | # | # | # | # | # |
| Homemaker or retired | 0.05 | -0.09 | -0.01 | 0.32 | 0.00 | -0.21 | 0.02 | -0.05 |
| Job seeking/unemployed/disabled | 0.98*** | -0.05 | -0.32 | -0.19 | 0.54*** | 0.15 | -0.06 | 0.59*** |
| Full-time student | -0.03 | -0.04 | 0.02 | 0.33 | -0.06 | -0.15 | -0.18 | -0.08 |
| Other | 0.17 | -0.51** | 0.37 | -0.16 | -0.09 | -0.07 | 0.17 | -0.03 |

| | Consequences | Timeline | Personal control | Treatment control | Identity | Concern | Coherence | Emotional representation |
|---------------------------------------|--------------|----------|------------------|-------------------|----------|---------|-----------|--------------------------|
| <i>Illness complexity</i> | | | | | | | | |
| Simple | # | # | # | # | # | # | # | # |
| Moderate | 0.24 | 0.83*** | 0.09 | 0.71*** | 0.14 | 0.33** | -0.09 | 0.03 |
| Complex | 0.81*** | 1.44*** | 0.03 | 0.62*** | 0.59*** | 0.62*** | -0.07 | 0.46*** |
| <i>NYHA functional class</i> | | | | | | | | |
| Class I ^a | # | # | # | # | # | # | # | # |
| Class II | 1.94*** | 0.78*** | -0.86*** | -0.35** | 2.05*** | 1.31*** | -0.35*** | 1.77*** |
| Class III | 3.72*** | 1.01*** | -1.72*** | -0.57** | 3.47*** | 2.06*** | -0.42** | 2.84*** |
| Class IV ^b | 4.49*** | 1.04*** | -2.42*** | -1.61*** | 4.49*** | 2.98*** | -0.68** | 3.75*** |
| <i>Ethnicity</i> | | | | | | | | |
| White/Caucasian | # | # | # | # | # | # | # | # |
| Middle-Eastern/Arabic | -0.20 | -0.82 | 0.50 | -0.43 | 0.15 | 0.52 | -0.77 | 0.36 |
| Asian | 0.52** | -1.26*** | 0.37 | 0.58 | 0.57** | 0.80 | -0.25 | 0.42 |
| Black/African-American | 0.78 | -0.45 | 0.19 | 0.24 | 1.49*** | 0.63 | 0.20 | 1.25 |
| Hispanic/Latino | 0.34 | -0.52 | 1.00** | -0.14 | 0.36 | 0.67 | -0.24 | 0.62 |
| Other | 0.25 | -0.03 | 0.96 | 0.39 | -0.39 | 0.73 | -0.54 | 0.38 |
| Proportion explained variances | | | | | | | | |
| R ² _{patient} | .34 | .07 | .06 | .03 | .34 | .12 | .03 | .18 |
| R ² _{country} | .01 | .06 | .01 | .03 | .02 | .12 | .01 | .01 |
| R ² _{total} | .35 | .19 | .09 | .07 | .36 | .25 | .05 | .20 |

Note. In all multivariate models, a random country effect was included. All coefficients are unstandardized. ^aNot limited during physical activities. ^bUnable to be physically active without experiencing discomfort. #: Reference category. R² was derived from the model chi-square. ** $p < .01$. *** $p < .001$.

Table 3.

Results from the GLMMs examining associations between illness perceptions and patient-reported outcomes.

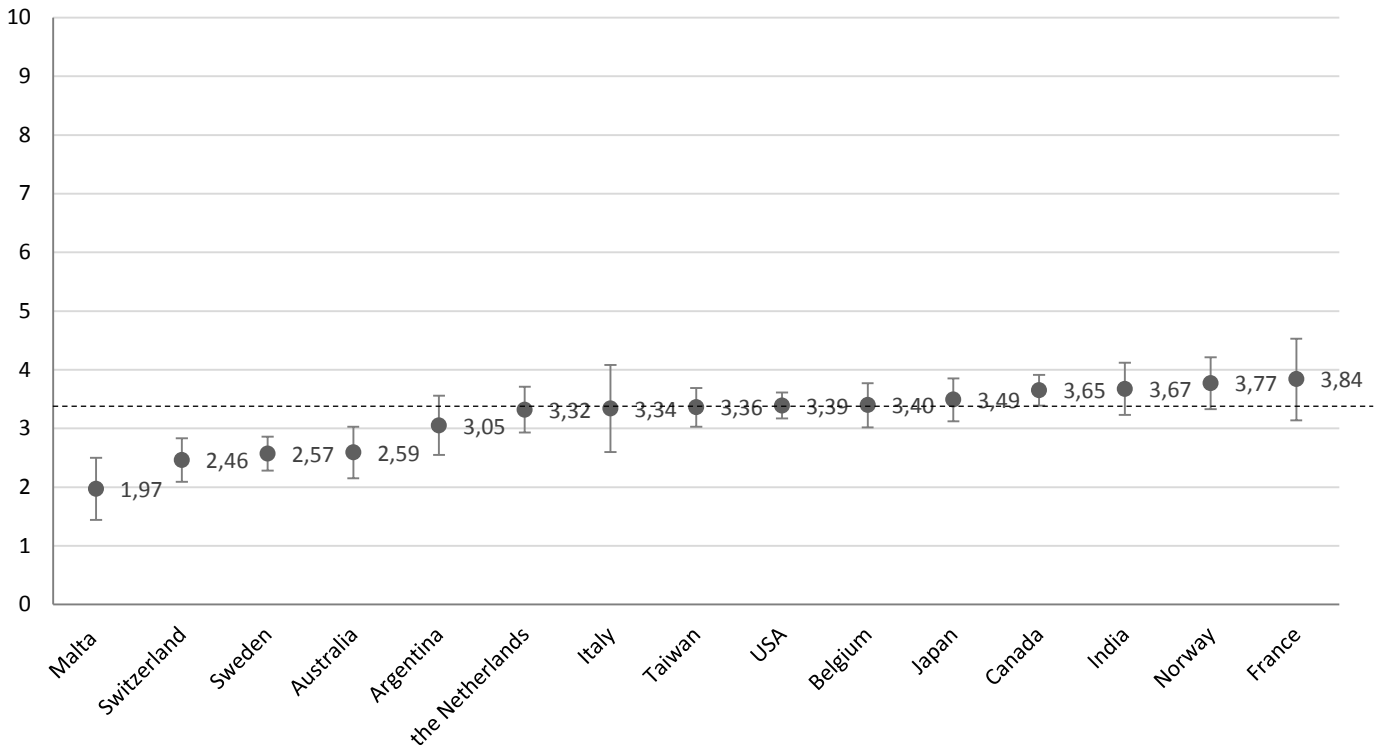
| | SWLS | HADS-D | HADS-A | PCS | MCS | EQ-VAS |
|--------------------------------|----------|----------|----------|----------|----------|----------|
| Patient characteristics | | | | | | |
| Sex | | | | | | |
| Men | -0.54** | 0.16 | -0.36** | 3.16*** | 2.51 | 0.42 |
| Women | # | # | # | # | # | # |
| Age | -0.03** | 0.02** | -0.02*** | -0.21*** | 0.04 | -0.09** |
| Marital Status | | | | | | |
| Married/ living with partner | # | # | # | # | # | # |
| Unmarried | -1.93*** | 0.14 | -0.07 | -0.45 | -0.60 | -0.49 |
| Divorced or widowed | -1.35** | 0.27 | 0.19 | -1.38 | -3.47** | -0.62 |
| Other | 1.56 | -0.83 | -0.93 | 1.17 | 9.51 | -0.28 |
| Educational level | | | | | | |
| Less than high school | -0.66 | 0.37 | -0.03 | -5.33*** | -1.50 | -4.29*** |
| High school | -0.86*** | 0.27 | -0.04 | -2.99*** | -0.51 | 0.25 |
| College degree | -0.65 | 0.30 | 0.19 | -1.51 | -0.88 | -0.14 |
| University degree | # | # | # | # | # | # |
| Employment Status | | | | | | |
| Part- or full-time work | # | # | # | # | # | # |
| Homemaker or retired | 1.03 | 0.10 | -0.06 | -2.42** | -2.16 | -1.00 |
| Job | -2.02*** | 0.91*** | 0.45 | -6.73*** | -5.20*** | -3.70 |
| Full-time student | 0.99** | -0.03 | 0.29 | 0.71 | 0.12 | 0.05 |
| Other | 1.19** | -0.10 | -0.42 | -1.42 | -0.15 | 0.90 |
| Illness complexity | | | | | | |
| Simple | # | # | # | # | # | # |
| Moderate | 0.25 | -0.14 | -0.11 | 0.19 | 1.21 | 0.32 |
| Complex | 0.37 | -0.60*** | -0.40 | 0.62 | 3.29*** | 0.54 |

| | SWLS | HADS-D | HADS-A | PCS | MCS | EQ-VAS |
|---|----------|----------|----------|-----------|-----------|-----------|
| NYHA functional class | | | | | | |
| Class I ^a | # | # | # | # | # | # |
| Class II | -0.22 | 0.26 | 0.15 | -7.49*** | -3.07*** | -1.80** |
| Class III | -1.23** | 1.20*** | 0.25 | -19.54*** | -8.23*** | -9.24*** |
| Class IV ^b | -2.33*** | 2.42*** | 1.65*** | -27.85*** | -16.81*** | -17.51*** |
| Ethnicity | | | | | | |
| White/Caucasian | # | # | # | # | # | # |
| Middle-Eastern/Arabic | -0.39 | 1.48** | 0.67 | -2.37 | -3.20 | -1.13 |
| Asian | -1.09 | 0.97*** | -0.09 | -0.95 | -1.31 | 0.22 |
| Black/African-American | -1.48 | 0.75 | -0.32 | -0.52 | -2.60 | -1.43 |
| Hispanic/Latino | -0.59 | 0.64 | 0.74 | 0.15 | -1.00 | -1.08 |
| Other | -0.90 | 1.31 | 0.85 | 0.92 | -4.89 | -2.84 |
| Illness perceptions | | | | | | |
| Consequences | -0.37*** | 0.09** | 0.00 | -1.45*** | -0.48** | -1.16*** |
| Timeline | 0.03 | 0.00 | 0.01 | 0.10 | 0.04 | -0.12 |
| Personal control | 0.12** | -0.04 | -0.05 | 0.18 | 0.28** | 0.19 |
| Treatment control | 0.12*** | -0.09*** | -0.06** | 0.28*** | 0.35*** | 0.34*** |
| Identity | -0.19*** | 0.11*** | 0.14*** | -1.79*** | -0.91*** | -1.13*** |
| Concern | 0.07 | -0.02 | 0.05 | -0.11 | 0.29** | 0.07 |
| Coherence | 0.29*** | -0.14*** | -0.15*** | 0.21 | 0.85*** | 0.40*** |
| Emotional representation | -0.46*** | 0.28*** | 0.47*** | -0.27** | -1.95*** | -0.47*** |
| Proportion explained variances | | | | | | |
| R ² _{patient} | .07 | .07 | .03 | .30 | .08 | .10 |
| R ² _{illness perceptions} | .16 | .17 | .22 | .27 | .23 | .17 |
| R ² _{country} | .03 | .01 | .01 | .04 | .00 | .00 |
| R ² _{total} | .34 | .34 | .33 | .67 | .43 | .43 |

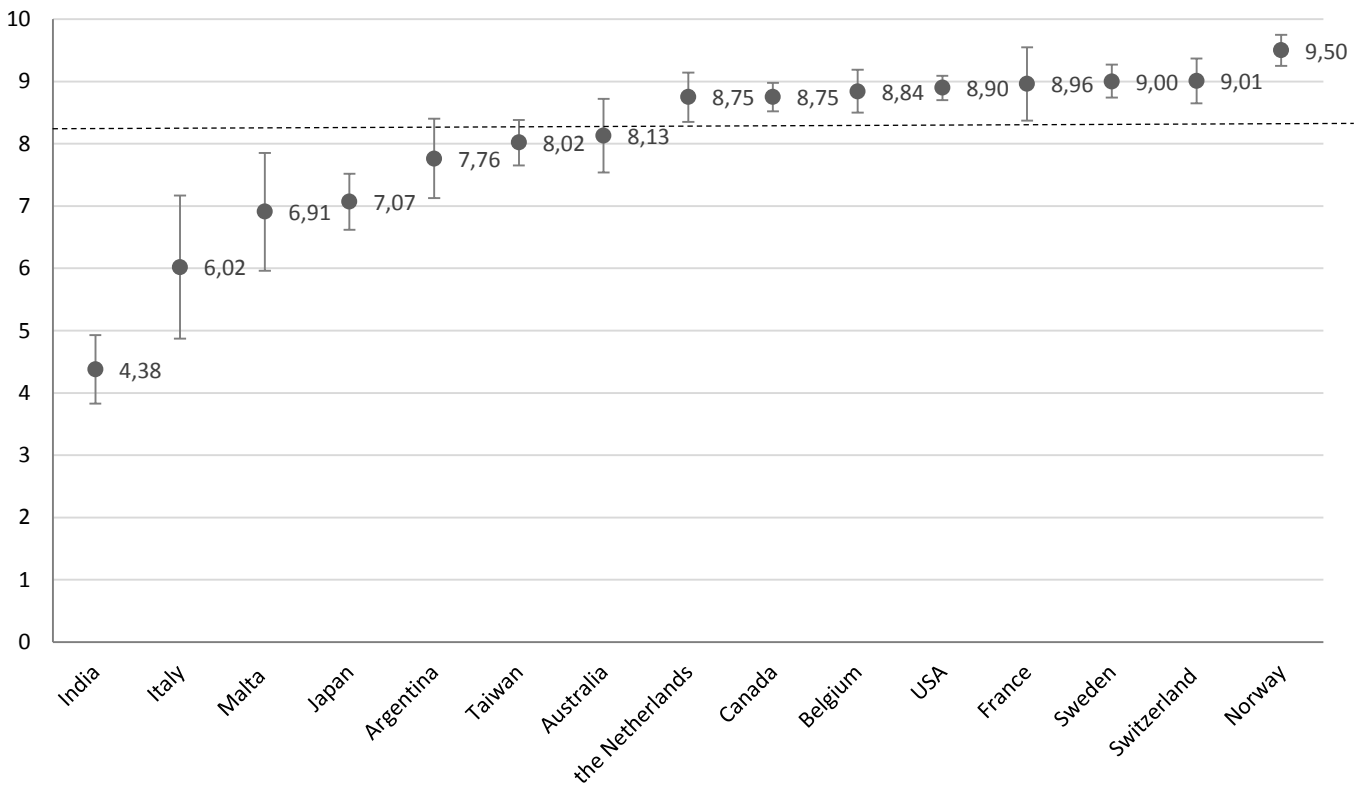
Note. In all multivariate models, a random country effect was included. SWLS= Satisfaction with Life Scale; HADS-D= Hospital Anxiety and Depression Scale – Depression; HADS-A= Hospital Anxiety and Depression Scale – Anxiety; PCS= Physical Component Summary; MCS= Mental Component Summary; EQ-VAS= EuroQol 5 Dimensions-Visual Analog Scale. All coefficients are unstandardized. #: Reference category. -: Not included in the analyses. R² was derived from the model chi-square. ***p* < .01. ****p* < .001.

Online Figure 1. Mean scores on all eight illness perceptions (with 95% confidence intervals) for each participating country: Consequences (Panel a), Timeline (Panel b), Personal control (Panel c), Treatment control (Panel d), Identity (Panel e), Concern (Panel f), Coherence (Panel g), and Emotional representation (Panel h).

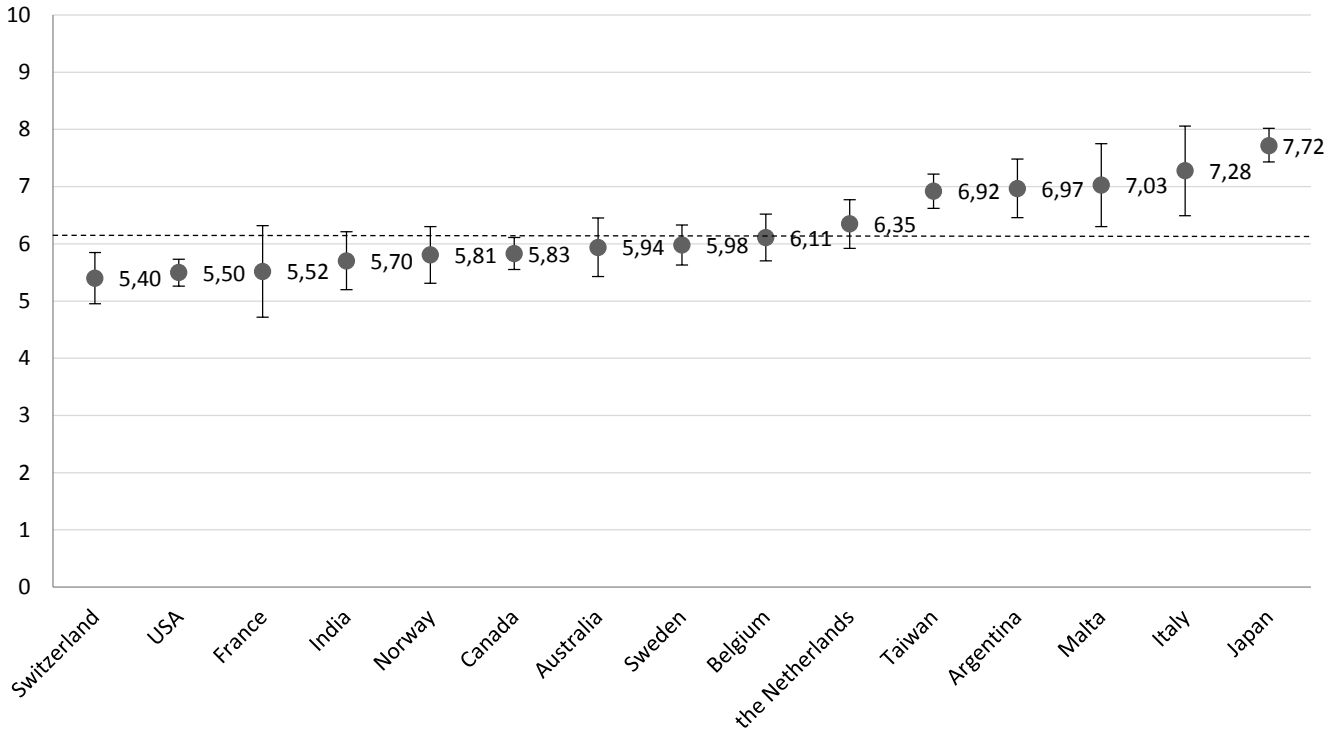
Panel a: Consequences



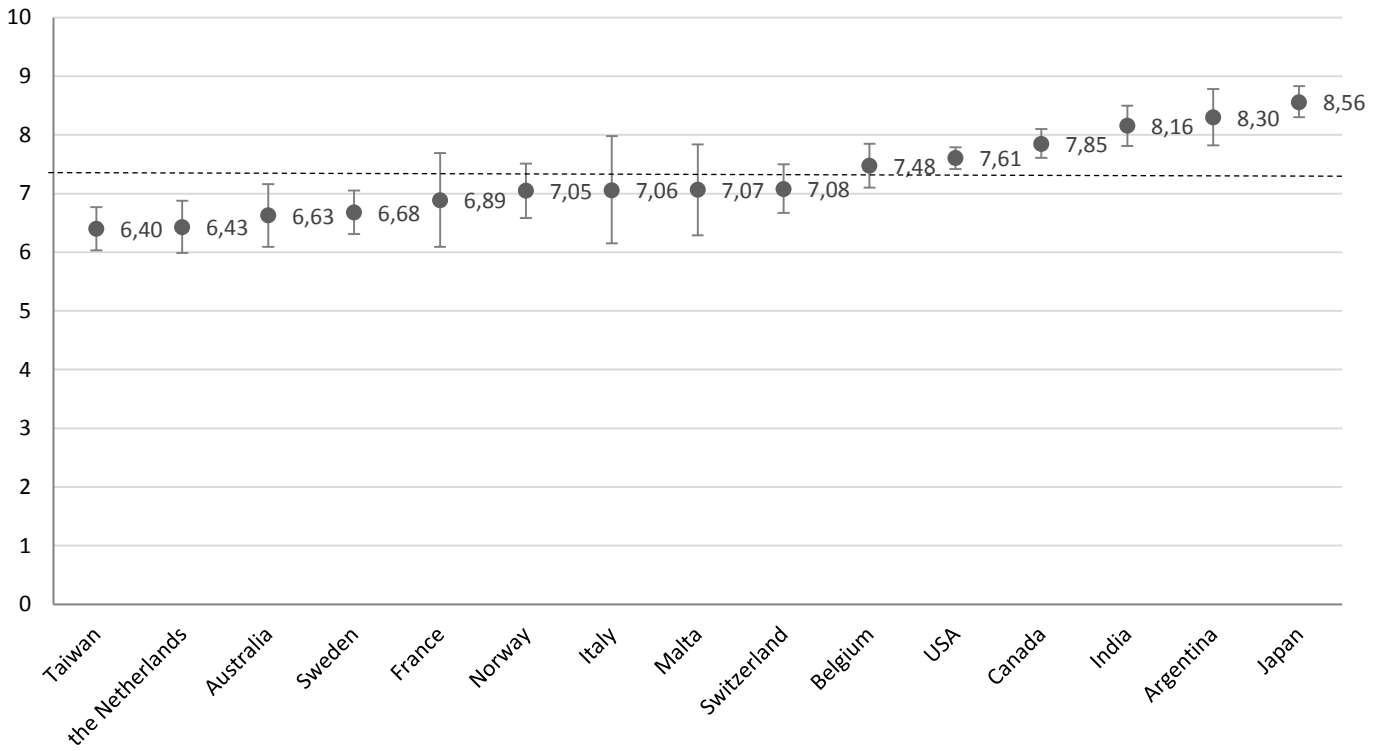
Panel b: Timeline



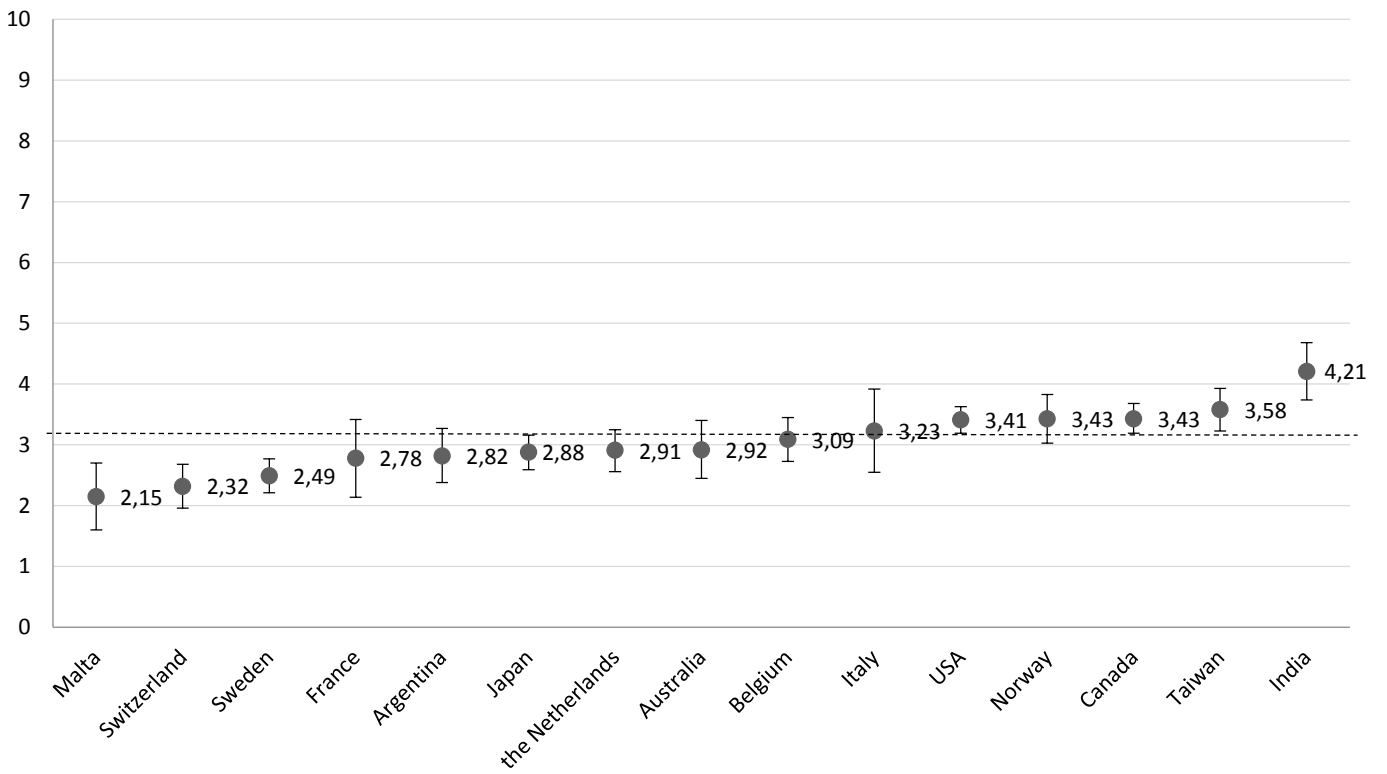
Panel c: Personal control



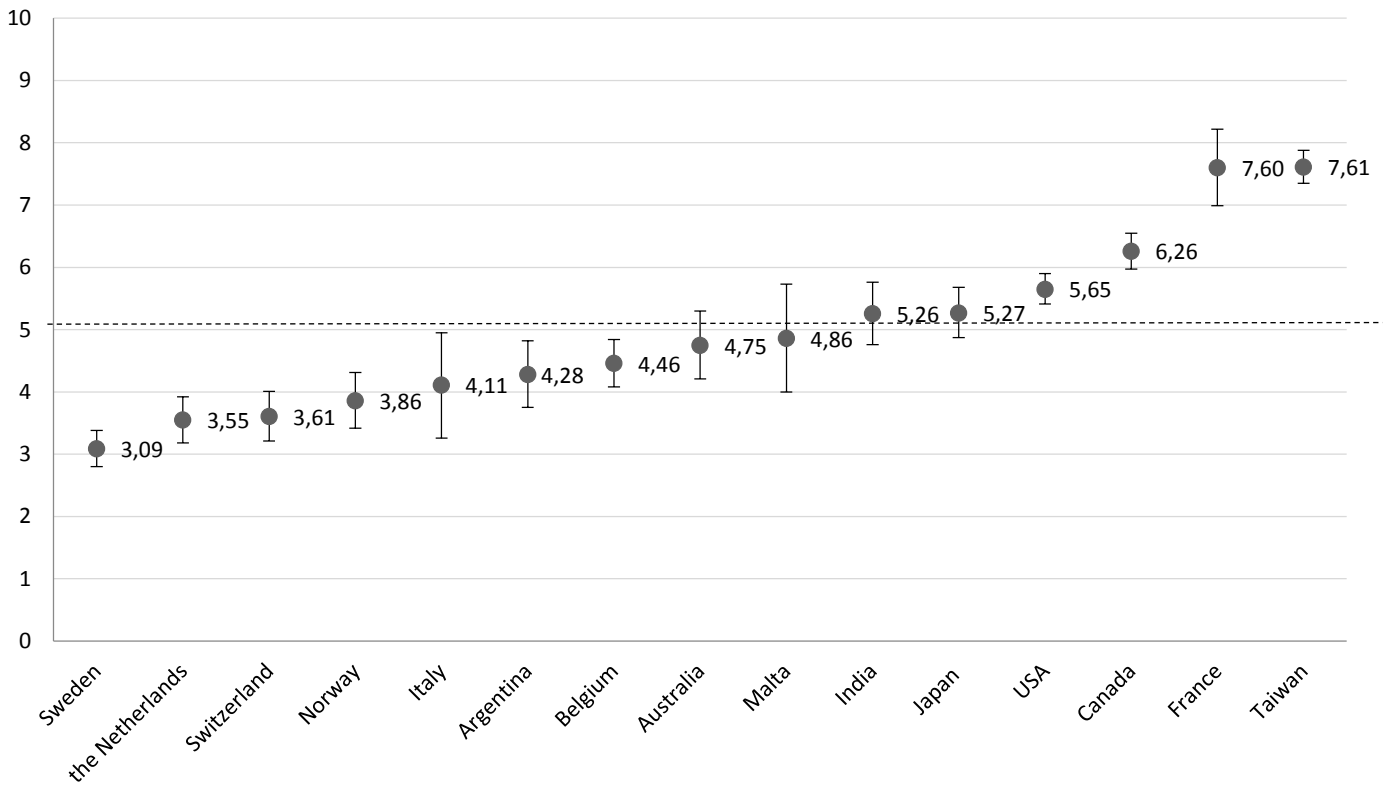
Panel d: Treatment control



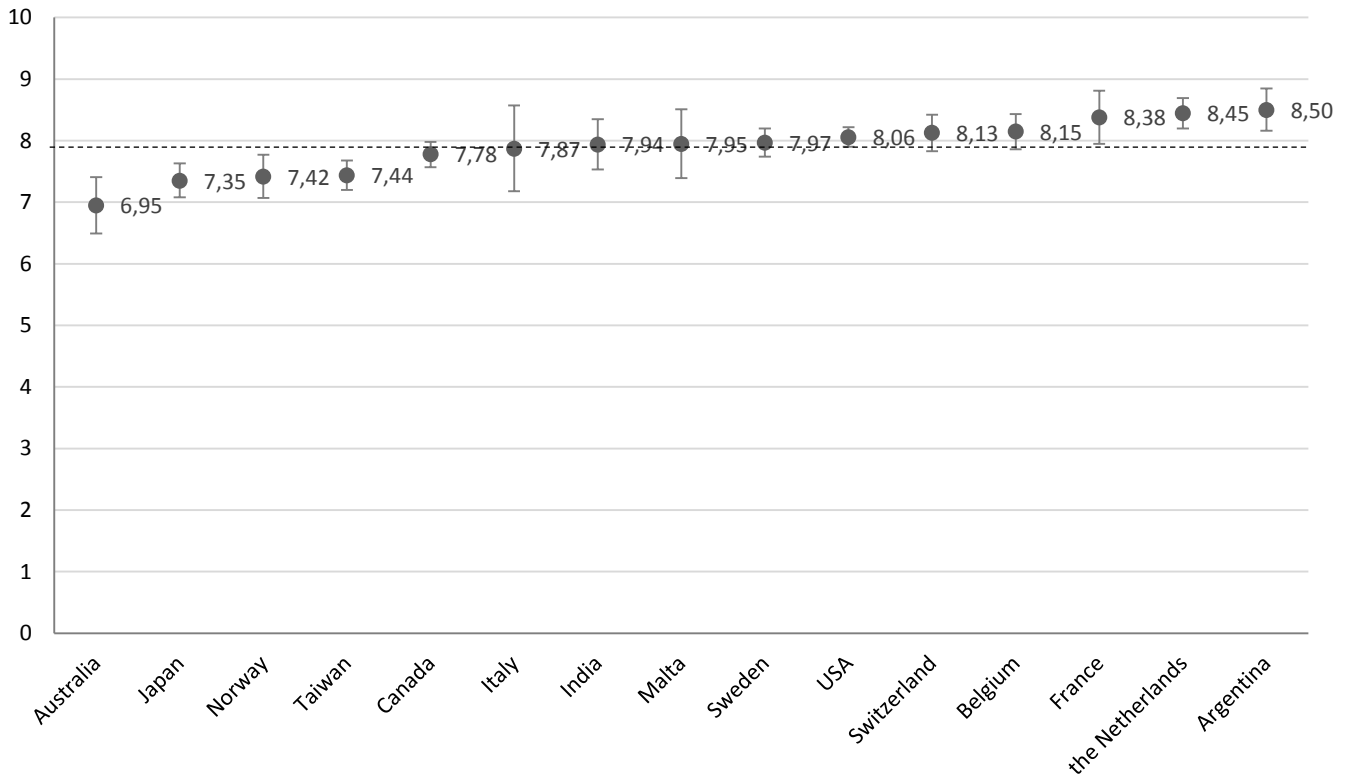
Panel e: Identity



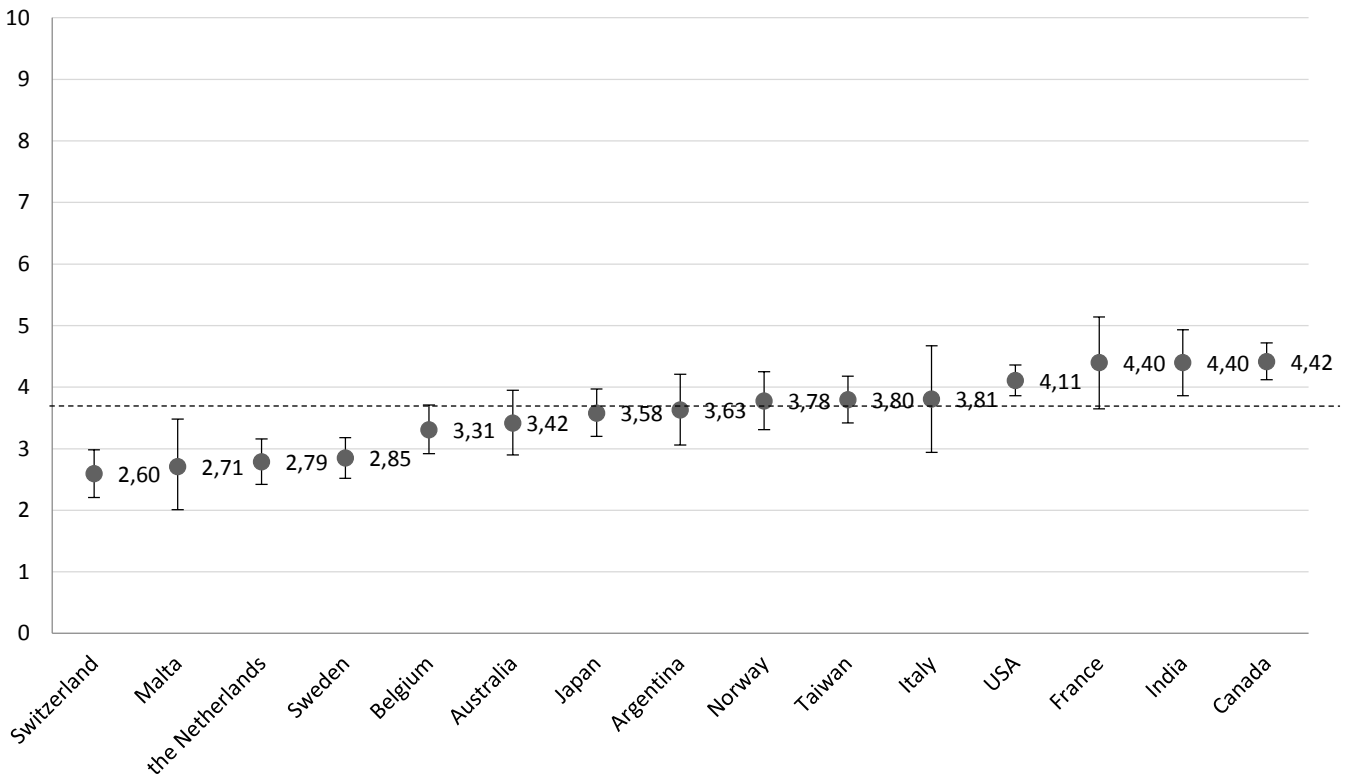
Panel f: Concern



Panel g: Coherence



Panel h: Emotional representation



Online Table 1.

Overall health system performance and Hofstede's cultural dimensions per country.

| | Health system performance | Cultural dimensions | | | | | |
|-----------------|---------------------------|----------------------|--------------------------------|----------------------------|-----------------------------|----------------------------------|--------------------------|
| | | Power distance index | Individualism vs. collectivism | Masculinity vs. femininity | Uncertainty avoidance index | Long- vs. short-term orientation | Indulgence vs. restraint |
| Argentina | .722 | 49 | 46 | 56 | 86 | 20 | 62 |
| Australia | .876 | 36 | 90 | 61 | 51 | 21 | 71 |
| Belgium | .915 | 65 | 75 | 54 | 94 | 82 | 57 |
| Canada | .881 | 39 | 80 | 52 | 48 | 36 | 68 |
| France | .994 | 68 | 71 | 43 | 86 | 63 | 48 |
| India | .617 | 77 | 48 | 56 | 40 | 51 | 26 |
| Italy | .991 | 50 | 76 | 70 | 75 | 61 | 30 |
| Japan | .957 | 54 | 46 | 95 | 92 | 88 | 42 |
| Malta | .978 | 56 | 59 | 47 | 96 | 47 | 66 |
| The Netherlands | .928 | 38 | 80 | 14 | 53 | 67 | 68 |
| Norway | .955 | 31 | 69 | 8 | 50 | 35 | 55 |
| Sweden | .908 | 31 | 71 | 5 | 29 | 53 | 78 |
| Switzerland | .916 | 34 | 68 | 70 | 58 | 74 | 66 |
| Taiwan | --- | 58 | 17 | 45 | 69 | 93 | 49 |
| USA | .838 | 40 | 91 | 62 | 46 | 26 | 68 |

Online Table 2.

Results from the GLMMs examining associations between country-specific characteristics and illness perceptions.

| | Consequences | Timeline | Personal control | Treatment control | Identity | Concern | Coherence | Emotional representation |
|--|--------------|----------|------------------|-------------------|----------|---------|-----------|--------------------------|
| Overall health system performance | 0.71 | 4.59 | 2.25 | -2.26 | -2.14 | 0.76 | -1.56 | -1.13 |
| Cultural dimensions | | | | | | | | |
| Power distance index | 0.00 | -0.03 | -0.03 | 0.00 | 0.02 | 0.06 | 0.02 | 0.02 |
| Individualism vs. collectivism | 0.02** | 0.00 | -0.01 | 0.00 | 0.00 | -0.01 | 0.00 | 0.01 |
| Masculinity vs. femininity | -0.01 | -0.01 | 0.00 | 0.01 | 0.00 | 0.01 | 0.00 | 0.00 |
| Uncertainty avoidance index | 0.01 | 0.01 | 0.02 | 0.01 | -0.01 | -0.01 | 0.00 | -0.01 |
| Long-term vs. short-term orientation | 0.00 | 0.02 | 0.00 | -0.01 | 0.00 | 0.00 | 0.00 | -0.01 |
| Indulgence vs. restraint | 0.00 | 0.05 | -0.02 | -0.01 | 0.01 | 0.04 | 0.01 | 0.00 |
| Proportion explained variances | | | | | | | | |
| R ² _{cultural} | .00 | .01 | .00 | .00 | .00 | .00 | .00 | .00 |
| R ² _{healthsystem} | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .00 |

Note. In all multivariate models, a random country effect was included. The multivariable models also contain all patient characteristics included in Table 2 as predictors, but results are reported only for country-specific characteristics. All coefficients are unstandardized. ^aNot limited during physical activities. ^bUnable to be physically active without experiencing discomfort. #: Reference category. R² was derived from the model chi-square. ** $p < .01$.