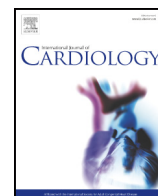




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Patient-reported outcomes in adults with congenital heart disease: Inter-country variation, standard of living and healthcare system factors[☆]

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ABSTRACT

Aims: Geographical differences in patient-reported outcomes (PROs) of adults with congenital heart disease (ConHD) have been observed, but are poorly understood. We aimed to: (1) investigate inter-country variation in PROs in adults with ConHD; (2) identify patient-related predictors of PROs; and (3) explore standard of living and healthcare system characteristics as predictors of PROs.

[☆] All author take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

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Multilevel analysis
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Methods and results: Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS) was a cross-sectional, observational study, in which 4028 patients from 15 countries in 5 continents were enrolled. Self-report questionnaires were administered: patient-reported health (12-item Short Form Health Survey; EuroQOL-5D Visual Analog Scale); psychological functioning (Hospital Anxiety and Depression Scale); health behaviors (Health Behavior Scale–Congenital Heart Disease) and quality of life (Linear Analog Scale for quality of life; Satisfaction With Life Scale). A composite PRO score was calculated. Standard of living was expressed as Gross Domestic Product per capita and Human Development Index. Healthcare systems were operationalized as the total health expenditure per capita and the overall health system performance. Substantial inter-country variation in PROs was observed, with Switzerland having the highest composite PRO score (81.0) and India the lowest (71.3). Functional class, age, and unemployment status were patient-related factors that independently and consistently predicted PROs. Standard of living and healthcare system characteristics predicted PROs above and beyond patient characteristics.

Conclusions: This international collaboration allowed us to determine that PROs in ConHD vary as a function of patient-related factors as well as the countries in which patients live.

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1. Introduction

In recent decades, the healthcare perspective has widened from attention on diseases and their pathophysiological mechanisms toward a broader conceptualization of health. The archetypal medical model has expanded and now includes a more holistic and comprehensive understanding of what it means to live with a chronic medical condition. Within the field of cardiology, this paradigm shift has raised the question how best to measure cardiovascular health and it has been argued that patients' perspectives should be incorporated within health metrics [1]. As a consequence, increased consideration of patient-reported outcome (PRO) measures has been advocated [2]. PROs are defined as “any reports of the status of a patient's health condition that come directly from the patient, without interpretation of the patient's response by a clinician or anyone else” [3]. PROs provide clinicians and researchers with valuable information about the health status of cardiovascular populations [1], and may predict hospitalization and mortality in specific groups of cardiac patients [4].

A rapidly growing group of adult cardiovascular patients is comprised of persons born with congenital heart disease (ConHD). The birth prevalence of ConHD is approximately 9 per 1000 newborns [5] and survival into adulthood has now reached 90% [6,7]. Given the achievement of excellent survival rates, the assessment of long-term functioning and well-being has gained importance [8] and PROs have become indispensable. The number of publications describing PROs in persons with ConHD has increased exponentially in recent decades [9,10]. However, the samples in these studies were usually small [9], thus hampering the generalizability of findings.

A recent meta-analysis on health-related quality of life (QoL), which is one example of a PRO, observed interesting geographical differences among adults with ConHD [9]. Specifically, patients from the Netherlands and Switzerland tended to have better scores than patients from North America, while random fluctuations were observed for other countries [9]. It is, however, unknown whether this geographical variability represents genuine differences between countries and healthcare systems or if this is merely a reflection of different methodological approaches. Indeed, accurate international comparisons are not possible without uniform study methodology. The question also remains how potential differences between countries can be understood. For healthcare professionals, administrators and policy-makers, it is important to know whether standard of living and healthcare system factors impact PROs. Furthermore, a broader perspective of PROs beyond health-related QoL would increase our understanding of the impact of patient and system characteristics.

Therefore, the aims of the present study were to: [1] investigate inter-country variation in PROs in a large international sample of adults with ConHD using a common methodology; [2] identify patient-related

predictors of PROs; and [3] explore standard of living and healthcare system characteristics as predictors of PROs.

2. Methods

To advance PRO research in ConHD, we established an international collaborative research group and conducted the Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS) in partnership with the International Society for Adult Congenital Heart Disease. APPROACH-IS is a cross-sectional study in which data were collected in 15 countries from 5 continents: Argentina, Australia, Belgium, Canada, France, India, Italy, Japan, Malta, Norway, Sweden, Switzerland, Taiwan, the Netherlands, and the United States of America (USA) [11]. The study complies with the Declaration of Helsinki and was approved by the institutional review board of the University Hospitals Leuven/KU Leuven Belgium (the coordinating center) as well as the local institutional review boards of participating centers when required. All participants provided written informed consent to participate. Detailed information on the rationale, design, and methods of APPROACH-IS has been described in a methods paper [11]. The study protocol was recorded at ClinicalTrials.gov: NCT02150603.

2.1. Study population and procedure

Patients were eligible if they met the following criteria: (i) diagnosis of ConHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that is present at birth and of actually or potentially functional significance; [12] (ii) 18 years of age or older; (iii) diagnosis established before adolescence; (iv) continued follow-up at a ConHD center or included in a national/regional registry; and (v) physical, cognitive, and language capabilities required to complete self-report questionnaires. Exclusion criteria were: (i) prior heart transplantation and (ii) primary pulmonary hypertension [11]. Eligible patients were mailed a questionnaire package or received it in clinic during an outpatient visit. Data collection ran from April 2013 through March 2015.

Overall, 4028 adults with ConHD were enrolled in APPROACH-IS, with a median age of 32 years and 53% were women (Table 1) [13]. Seventy-four percent of patients had a white or Caucasian background, 64% were working part- or full-time, and 51% were married or living with a partner. Forty-nine percent of patients had moderately complex ConHD and 54% reported being in NYHA Class I. A detailed description of patient characteristics per country has been previously published [13].

2.2. Measures

Self-report questionnaires were administered to capture information on four PRO domains: (i) perceived health status using the 12-item Short Form Health Survey [14] and the EuroQOL-5D Visual Analog Scale; [15] (ii) psychological functioning using the Hospital Anxiety and Depression Scale; [16] (iii) health behaviors using the Health-Behavior Scale–Congenital Heart Disease; [17] and (iv) QoL using a Linear Analog Scale; [18] and the Satisfaction With Life Scale [19]. Online Table 1 provides an expanded definition of the domains as applied in APPROACH-IS as well as the interpretation of scores for the individual questionnaires. Questionnaires have been subject for previous cross-cultural validation. Further details on the measures and their psychometric properties are provided in the APPROACH-IS methods paper [11].

2.3. Standard of living

We expressed the standard of living of each country in terms of the Gross Domestic Product based on purchasing power parity per capita and the Human Development Index. Gross Domestic Product based on purchasing power parity per capita is an indicator of the level of economic welfare in a particular country. It expresses the economic performance of a country, while accounting for cost of living and inflation rates. We used data

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