

# Quality of Life of Adults With Congenital Heart Disease in 15 Countries



## Evaluating Country-Specific Characteristics

Silke Apers, PhD,<sup>a</sup> Adrienne H. Kovacs, PhD,<sup>b</sup> Koen Luyckx, PhD,<sup>c</sup> Corina Thomet, MSc,<sup>d</sup> Werner Budts, MD, PhD,<sup>e</sup> Junko Enomoto, PhD,<sup>f</sup> Maayke A. Sluman, MD,<sup>g</sup> Jou-Kou Wang, MD, PhD,<sup>h</sup> Jamie L. Jackson, PhD,<sup>i</sup> Paul Khairy, MD, PhD,<sup>j</sup> Stephen C. Cook, MD,<sup>k</sup> Shanthi Chidambarathanu, MD,<sup>l</sup> Luis Alday, MD,<sup>m</sup> Katrine Eriksen, MSc,<sup>n</sup> Mikael Dellborg, MD, PhD,<sup>o,p</sup> Malin Berghammer, PhD,<sup>o</sup> Eva Mattsson, MD, PhD,<sup>q</sup> Andrew S. Mackie, MD,<sup>r</sup> Samuel Menahem, MD,<sup>s</sup> Maryanne Caruana, MD,<sup>t</sup> Gruschen Veldtman, MD,<sup>u</sup> Alexandra Soufi, MD,<sup>v</sup> Anitra W. Romfh, MD,<sup>w</sup> Kamila White, PhD,<sup>x</sup> Edward Callus, PhD,<sup>y</sup> Shelby Kutty, MD,<sup>z</sup> Steffen Fieuws, PhD,<sup>aa</sup> Philip Moons, PhD,<sup>a,o</sup> on behalf of the APPROACH-IS consortium and ISACHD

### ABSTRACT

**BACKGROUND** Measuring quality of life (QOL) is fundamental to understanding the impact of disease and treatment on patients' lives.

**OBJECTIVES** This study aimed to explore QOL in an international sample of adults with congenital heart disease (CHD), the association between patient characteristics and QOL, and international variation in QOL and its relationship to country-specific characteristics.

**METHODS** We enrolled 4,028 adults with CHD from 15 countries. QOL was assessed using a linear analog scale (LAS) (0 to 100) and the Satisfaction with Life Scale (SWLS) (5 to 35). Patient characteristics included sex, age, marital status, educational level, employment status, CHD complexity, and patient-reported New York Heart Association (NYHA) functional class. Country-specific characteristics included general happiness and 6 cultural dimensions. Linear mixed models were applied.

**RESULTS** Median QOL was 80 on the LAS and 27 on the SWLS. Older age, lack of employment, no marriage history, and worse NYHA functional class were associated with lower QOL ( $p < 0.001$ ). Patients from Australia had the highest QOL (LAS: 82) and patients from Japan the lowest (LAS: 72). Happiness scores and cultural dimensions were not associated with variation in QOL after adjustment for patient characteristics and explained only an additional 0.1% of the variance above and beyond patient characteristics ( $p = 0.56$ ).

**CONCLUSIONS** This large-scale, international study found that overall QOL in adults with CHD was generally good. Variation in QOL was related to patient characteristics but not country-specific characteristics. Hence, patients at risk for poorer QOL can be identified using uniform criteria. General principles for designing interventions to improve QOL can be developed. (J Am Coll Cardiol 2016;67:2237-45) © 2016 by the American College of Cardiology Foundation.

From the <sup>a</sup>KU Leuven, University of Leuven, Department of Public Health and Primary Care, Leuven, Belgium; <sup>b</sup>Peter Munk Cardiac Centre, University Health Network, University of Toronto, Toronto, Canada; <sup>c</sup>KU Leuven, University of Leuven, School of Psychology and Child and Adolescent Development, Leuven, Belgium; <sup>d</sup>University Hospital Bern, Center for Congenital Heart Disease, Bern, Switzerland; <sup>e</sup>KU Leuven, University of Leuven, University Hospitals Leuven, Division of Congenital and Structural Cardiology, Leuven, Belgium; <sup>f</sup>Department of Adult Congenital Heart Disease, Chiba Cardiovascular Center, Chiba, Japan; <sup>g</sup>Academic Medical Center, Department of Cardiology, Amsterdam, the Netherlands; <sup>h</sup>Department of Pediatrics, National Taiwan University Hospital, Taipei, Taiwan; <sup>i</sup>Center for Biobehavioral Health, Nationwide Children's Hospital, Columbus, Ohio; <sup>j</sup>Adult Congenital Heart Center, Montreal Heart Institute, Université de Montréal, Montreal, Canada; <sup>k</sup>Adult Congenital Heart Disease Center, Heart Institute, Children's Hospital of Pittsburgh of UPMC, Pittsburgh, Pennsylvania; <sup>l</sup>Frontier Lifeline Hospital (Dr. K. M. Chierian Heart Foundation), Chennai, India; <sup>m</sup>Division of Cardiology, Hospital de Niños, Córdoba, Argentina; <sup>n</sup>Oslo University Hospital, Rikshospitalet, Oslo, Norway; <sup>o</sup>The Sahlgrenska Academy at University of Gothenburg, Institute of Medicine, Gothenburg, Sweden, and Centre for Person-Centred Care (GPCC), University of Gothenburg, Gothenburg, Sweden; <sup>p</sup>Adult Congenital Heart Unit, Sahlgrenska University Hospital/Östra and Institute for Medicine, The Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden; <sup>q</sup>Karolinska University Hospital, Stockholm, Sweden; <sup>r</sup>Stollery Children's Hospital, University of Alberta, Edmonton, Canada; <sup>s</sup>Monash Heart, Monash Medical Centre, Monash University, Melbourne, Australia; <sup>t</sup>Department of Cardiology, Mater Dei Hospital, Birkirkara Bypass, Malta; <sup>u</sup>Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; <sup>v</sup>Department



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## ABBREVIATIONS AND ACRONYMS

**CHD** = congenital heart disease

**GLMM** = general linear mixed model

**IQR** = interquartile range

**LAS** = linear analog scale

**NYHA** = New York Heart Association

**PRO** = patient-reported outcome

**QOL** = quality of life

**SWLS** = Satisfaction with Life Scale

Living well is as important to most people as living longer. Therefore, the concept of quality of life (QOL) has gained much attention in biomedical science over the past few decades (1,2). In this respect, comprehensive assessments of QOL and other patient-reported outcomes (PROs) have become indispensable (1-4). PROs are descriptions coming directly from patients about how they feel or function in relation to their health and well-being (5), and have been associated with important medical outcomes (6). Although the cardiology community recognizes that it is imperative to assess PROs to better understand

the impact of health and disease, these outcomes remain underused in cardiovascular clinical trials (7). Moreover, many studies on PROs in the larger field of chronic diseases use poor-quality instruments (8).

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In the cardiac subspecialty of congenital heart disease (CHD), QOL research commenced 40 years ago and has increased exponentially over time (9). To date, more than 230 QOL studies in CHD conducted in 35 countries have been published (9). However, a critical appraisal revealed that most articles on QOL had substantial conceptual and methodological deficits (9), yielding inconsistent results (10,11). Such inconsistencies may be attributable to differences in methodological approaches or to genuine differences in QOL between patients living in different countries (12). Furthermore, these studies investigated only demographic and/or medical predictors of QOL, leaving population measures or cultural dimensions unaddressed. It is reasonable to hypothesize that QOL scores among adults with CHD might be higher in countries known to have higher QOL in the general population (e.g., Denmark, Norway, or Switzerland). This possibility, however, has never been investigated.

To gain a better understanding of QOL in patients with CHD worldwide, it is critical to examine QOL in different countries using a uniform research methodology. This allows us to ascertain whether there are genuine differences in QOL in patients living in different countries, independent of methodological considerations. Furthermore, it enables us to evaluate whether country-specific characteristics explain QOL above and beyond patient characteristics. Therefore, the aims of this study were to: 1) describe QOL in a large international sample of adults with CHD; 2) investigate the association between QOL and patient characteristics (i.e., sociodemographic and medical variables); and 3) explore variation in QOL across countries and investigate the relationship between QOL and country characteristics (i.e., general population happiness and cultural dimensions).

## METHODS

We established an international collaborative research group and undertook APPROACH-IS (Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease - International Study). APPROACH-IS is a cross-sectional, multilevel study with a standardized protocol conducted in partnership with the International Society for Adult Congenital Heart Disease (12). 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. The study was approved by the institutional review board of the University Hospitals Leuven/KU Leuven Belgium (the coordinating center) and the local institutional review board of participating centers when required. All subjects provided written informed consent to participate. Detailed information on the rationale, design, and methods is available in a published methods paper (12).

**STUDY POPULATION AND PROCEDURE.** A questionnaire package was sent by surface mail or distributed in

of Congenital Heart Disease, Louis Pradel Hospital, Hospices civils de Lyon, Lyon, France; <sup>w</sup>Stanford University, Department of Pediatrics and Medicine, Division of Pediatric Cardiology and Cardiovascular Medicine, Palo Alto, California; <sup>x</sup>Washington University and Barnes Jewish Heart & Vascular Center, University of Missouri, Saint Louis, Missouri; <sup>y</sup>Department of Pediatric Cardiology and Adult with Congenital Heart Defect, IRCCS Policlinico San Donato, Milan, Italy; <sup>z</sup>University of Nebraska Medical Center/Children's Hospital and Medical Center, Omaha, Nebraska; and the <sup>aa</sup>KU Leuven, University of Leuven and Universiteit Hasselt, Interuniversity Institute for Biostatistics and Statistical Bioinformatics, Leuven, Belgium. This work was supported by the Research Fund-KU Leuven (Leuven, Belgium) through grant OT/11/033; by the Swedish Heart-Lung Foundation (Sweden) through grant number 20130607; by the University of Gothenburg Centre for Person-centred Care (Gothenburg, Sweden); and by the Cardiac Children's Foundation (Taiwan) through grant CCF2013.02. Furthermore, this work was endorsed by and conducted in collaboration with the International Society for Adult Congenital Heart Disease (ISACHD). The authors have reported that they have no relationships relevant to the contents of this paper to disclose.

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