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RESEARCH LETTER

Patient-reported outcomes in the aging population of adults with congenital heart disease: results from APPROACH-IS

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The congenital heart disease (CHD) population now comprises an increasing number of older persons in their 6th decade of life and beyond. We cross-sectionally evaluated patient-reported outcomes (PROs) in persons with CHD aged 60 years or older, and contrasted these with PROs of younger patients aged 40–59 years and 18–39 years. Adjusted for demographic and medical characteristics, patients ≥60 years had a lower Physical Component Summary, higher Mental Component Summary, and lower anxiety (Hospital Anxiety and Depression Scale-Anxiety) scores than patients in the two younger categories. For satisfaction with life, older persons had a higher score than patients aged 40–59 years. Registration: ClinicalTrials.gov NCT02150603.

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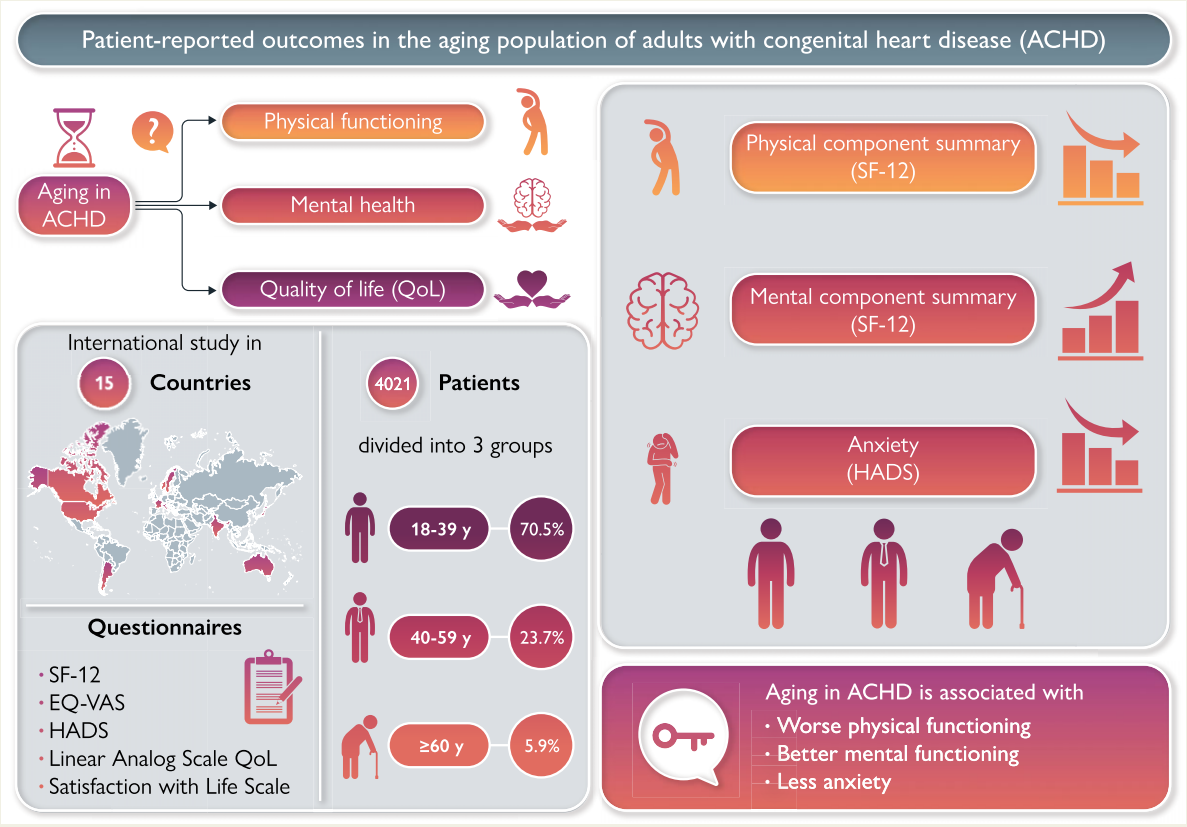
Graphical Abstract



Keywords Aging • Functioning • Heart defects, congenital • Mental health • Patient-reported outcomes • Quality of life

Novelty

- This study gives first time evidence about patient-reported outcomes in older people with congenital heart disease (CHD)
- Older patients with CHD report less anxiety and better mental health than their younger counterparts
- Patients with CHD aged 60 years or older reported greater life satisfaction compared with patients in their 40s or 50s.

Introduction

Over the past five decades, the life expectancy of patients with congenital heart disease (CHD) has increased spectacularly. Today, in developed countries, more than 90% of children born with CHD are expected to survive into adulthood.[1,2] The life expectancy has improved to the extent that the number of adults living with CHD now exceeds the number of children in higher-resourced countries.[3] Notably, there is an increasing proportion of older adults reaching the 6th decade of life and beyond. By 2030 it is estimated that 11% of the European adult CHD population will be aged 60 years or older.[4] Early empirical data show that older persons with CHD constitute a specific group of individuals with high morbidity, healthcare utilization, and mortality.[5–8] However, patient-reported outcomes (PROs) in older patients have been relatively unexplored. PROs are typically defined as '*any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else*'.[9] The aims of the present study were (i) to describe PROs in older persons with CHD and (ii) to contrast these with PROs of younger age cohorts.

Methods

This analysis is a substudy of the Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS). APPROACH-IS was a cross-sectional study conducted in 15 countries of 5 continents: Argentina,

Australia, Belgium, Canada, France, India, Italy, Japan, Malta, Norway, Sweden, Switzerland, Taiwan, the Netherlands, and the United States of America (USA).[10] The methods of APPROACH-IS have been extensively described in a protocol paper.[10] In short, we included 4,028 adults (≥18 years) with CHD who were followed-up at a CHD center or included in a national/regional registry, and who had the physical, cognitive, and language capabilities required to complete self-report questionnaires.[10,11] The study was approved by the Institutional Review Board of the University Hospitals Leuven/KU Leuven Belgium (coordinating centre) and by the local institutional review boards of the participating centers (when required). Informed consent was obtained from each participating patient. The study protocol was registered at ClinicalTrials.gov: NCT02150603.

Demographic data were collected through self-report questionnaires. In line with a prior study on older persons with CHD,[6] we categorized patients into three age cohorts: ≥60 years; 40–59 years; and 18–39 years. We assessed three domains of PROs using valid and reliable self-report questionnaires: (i) perceived physical and mental health status using the 12-item Short Form Health Survey (SF-12)[12] and the EuroQOL-5D Visual Analog Scale (EQ-VAS);[13] (ii) psychological distress using the Hospital Anxiety and Depression Scale (HADS);[14] and (iii) quality of life using a Linear Analogue Scale (QOL-LAS)[15] and the Satisfaction With Life Scale (SWLS).[16] Expanded definitions of the domains and the interpretation of scores of the questionnaires are provided in Supplementary material online, *Table S1*. Eligible patients were mailed a questionnaire package or completed surveys during an outpatient visit. Data collection ran from April 2013 through March 2015.

Data analysis was performed using IBM SPSS Statistics for Windows, version 28 (IBM Corp., Armonk, NY, USA). Patient-reported outcome scores were expressed as means and standard deviations. Demographic and medical background variables were compared across the age cohorts using the χ^2 test. Differences in PROs across the age cohorts were tested through multivariable general linear mixed models, adjusted for sex; educational level; employment status; marital status; patient-reported NYHA status; and complexity of the heart defect. A two-level structure in which patients were nested within countries was modelled. A Benjamini–Hochberg adjusted *P*-level (aka *q*-value) <0.05 was used as the cut-off for statistical significance to avoid inflation of Type 1 error. Statistical tests were two-sided.

Results

The age was documented in 4021 patients of the entire sample (99.8%); 236 were 60 years or older (5.9%), 952 were aged 40–59 years (23.7%), and 2833 were aged 19–39 years (70.5%). The demographic and medical characteristics of the age cohorts are presented in Supplementary material online, *Table S2*. As expected, age cohorts differed on all background variables, except for sex.

The mean scores and standard deviations of PROs across age cohorts are presented in *Figure 1*. Adjusted for demographic and medical characteristics, patients aged 60 years or older had lower physical health status (as per the SF-12), although better mental health status (SF-12) and fewer anxiety symptoms (on the HADS) than patients of the two younger age cohorts. Older patients also reported higher life satisfaction (as per the SWLS) compared with patients aged 40–59 years (*Table 1*).

Discussion

The population of patients with CHD is aging, with important repercussions for cardiovascular and systemic complications.[17] There are indications that people with CHD age physiologically at a faster pace than non-afflicted peers.[18] The functional consequences of this premature aging have yet to be documented. In the present study, when analyses were adjusted for demographic and medical variables, we found that patients with CHD aged 60 years or older had worse physical functioning than patients from younger age cohorts but had less anxiety and better mental health status. It is important to mention that the mean values of perceived mental health status did not seem to differ across the age cohorts. It was only after adjustment for patient characteristics that the mental health status of older patients emerged as being better than younger cohorts. Indeed, the demographic and clinical profile of older patients, being education level, employment status, marital status, New York Heart Association functional class, and complexity of CHD, was substantially different from that of younger patients. A better mental health status in older individuals is in line with observations in the general population and other medical conditions, from which it is known that physical functioning tends to decrease with aging, whereas emotional well-being improves.[19–21] The paradox of better mental health scores in older persons might be partially explained by a 'response shift'. Response shift is the change in the meaning of one's self-evaluation of a target construct as a result of a change in internal standards and values, or a redefinition of the target construct.[22] Further, there are also brain alterations that induce changes in anxiety.[23] Consequently, a lower prevalence of anxiety disorders has also been documented in the general population.

A factor that might contribute to lower physical health status of older persons with CHD is the development of sarcopenia, which is the age-associated loss of skeletal muscle mass and function.[24] It is characterized by the degenerative loss of skeletal muscle mass, quality, and strength.[25] Primary sarcopenia is age-related, when no other specific cause is evident, whereas in secondary sarcopenia, causes other than or in addition to ageing are evident.[25] In CHD, secondary sarcopenia has been observed, probably as a result of the systemic impact of the heart defect and the occurrence of age-related morbidities.[26,27] For instance, a study that included patients with simple and complex CHD with a mean age of 37 years found a prevalence of sarcopenia of 16%.[26] Another study, in which only patients with complex heart defects with a mean age of 36 years were included, found a prevalence of 51%.[27] This high prevalence of sarcopenia is consistent with impaired skeletal muscle function that has been previously observed in complex CHD,[28] which likely reflects altered muscular oxygenation kinetics.[29]

A related concept is frailty, which is defined as '*a significant decline in functional reserve, resistance, and resilience of multiple organ systems, and the resultant extreme vulnerability of the individual to endogenous and exogenous stressors (such as infection, injury or surgery, or some medicines), leading to a higher risk of accelerated functional decline and adverse health-related outcomes*'.[30] To date, frailty has not been comprehensively investigated in CHD. However, in the international APPROACH-IS II project that is currently underway, frailty is being assessed in patients with moderate or complex CHD aged 40 years or older (https://clinicaltrials.gov/ct2/show/NCT04902768).

The APPROACH-IS project had several methodological strengths. More than 4000 patients from 15 countries were included; there was a high degree of complete data; and we used valid and reliable PRO instruments.[11,31] However, there were also some methodological

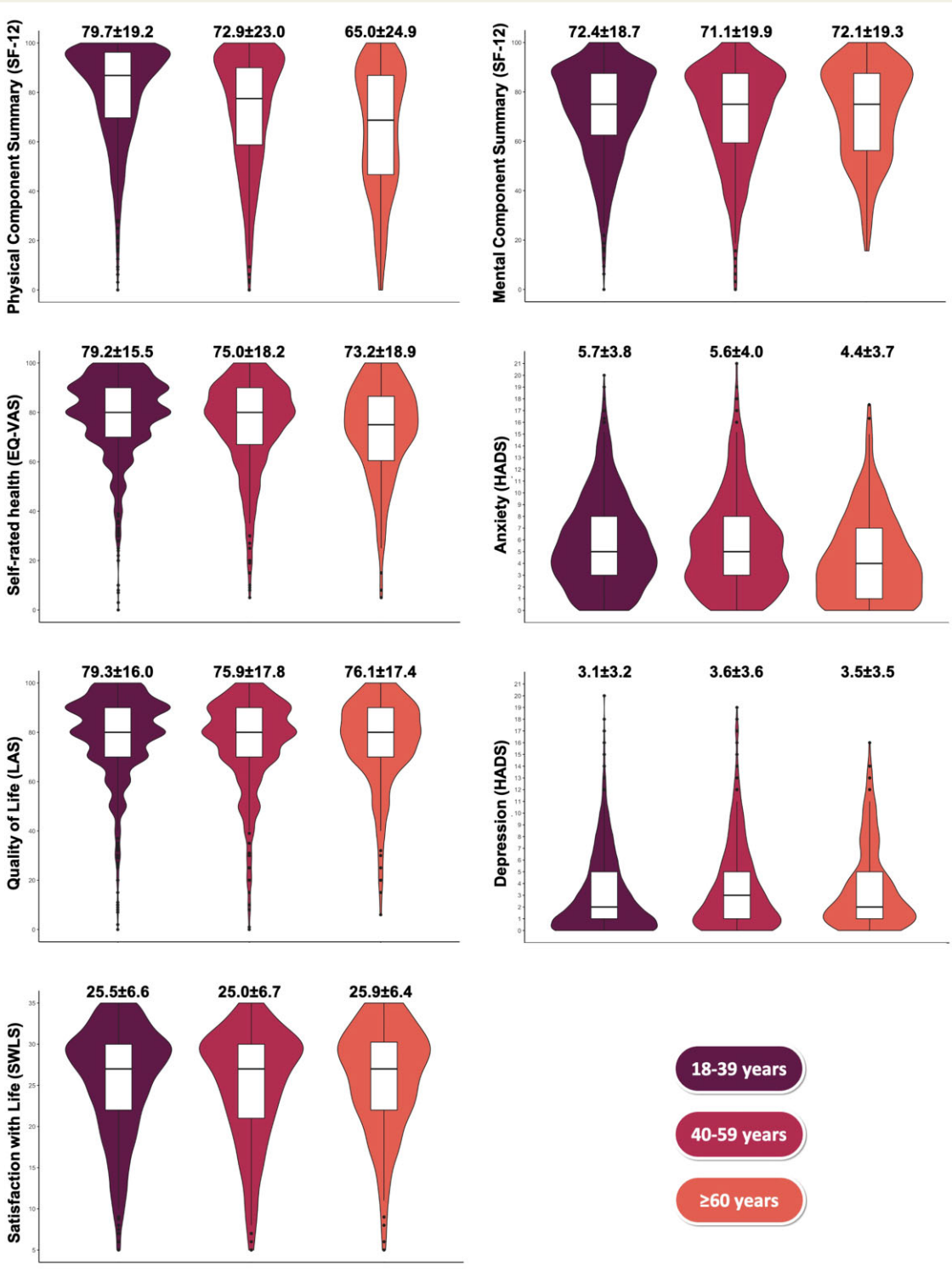


Figure 1 Patient-reported outcomes of adults with congenital heart disease stratified by age cohort.

limitations. APPROACH-IS was a cross-sectional study, and thus causality cannot be determined. Patients who did not have the physical or mental capacities to complete self-report questionnaires were ineligible for inclusion, which may have introduced a bias. This bias was, however, believed to be small because a comparison of participants and non-participants in the Swedish branch of APPROACH-IS revealed only small differences in demographic and clinical data.[32] Since we did not collect data on PROs in a control group, we are not able to directly compare the data of our patients with those in the general population.

Table 1 Differences in patient-reported outcomes between patients with congenital heart disease aged ≥60 years vs. younger age cohorts

Variables	Estimate[a] (*q*-value)[b] 40–59 years vs. ≥60 years	Estimate[a] (*q*-value)[b] 18–39 years vs. ≥60 years
SF-12 Physical Component Summary (PCS)	4.9 (<0.0001)	10.2 (<0.001)
SF-12 Mental Component Summary (MCS)	−4.6 (0.006)	−4.3 (0.009)
EuroQOL-5D Visual Analogue Scale (EQ-VAS)	−0.5 (0.771)	2.2 (0.141)
Hospital Anxiety and Depression Scale – Anxiety (HADS-A)	1.2 (<0.001)	1.5 (<0.001)
Hospital Anxiety and Depression Scale – Depression (HADS-D)	0.4 (0.212)	−0.1 (0.801)
Quality of Life - Linear Analogue Scale (QOL-LAS)	−2.1 (0.178)	0.5 (0.782)
Satisfaction with Life Scale (SWLS)	−1.3 (0.036)	−0.7 (0.226)

[a]Multivariable general linear mixed models (GLMMs), adjusted for sex; educational level; employment status; marital status; patient-reported NYHA status; and complexity of the heart defect.
[b]*q*-value is the Benjamini–Hochberg adjusted *P*-value.

In conclusion, older adults with CHD reported lower physical health status than patients from younger age cohorts. However, they also reported fewer anxiety symptoms and better emotional health status than younger patients. These findings based on PROs suggest that assisting the elderly with CHD to maintain or improve their physical functioning is essential to care for this growing population. Further, we need research to better understand how anxiety shifts across the lifespan and to tailor interventions accordingly.

Supplementary material

Supplementary material is available at *European Journal of Cardiovascular Nursing*.

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Conflict of interest: None of the authors have a conflict of interest.

Data availability

The data underlying this article can be shared on reasonable request to the corresponding author.

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