Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

HHS Public Access

Author manuscript

JACC Adv. Author manuscript; available in PMC 2024 June 06.

Published in final edited form as:

JACC Adv. 2024 May ; 3(5): . doi:10.1016/j.jacadv.2024.100917.

Key Psychosocial Health Outcomes and Association With Resilience Among Patients With Adult Congenital Heart Disease

Jill M. Steiner, MD, MS[a], **Katherine Nassans, MS**[b], **Lyndia Brumback, PHD**[c], **Karen K. Stout, MD**[b], **Chris T. Longenecker, MD**[d], **Joyce P. Yi-Frazier, PHD**[e], **J. Randall Curtis, MD, MPH**[f], **Abby R. Rosenberg, MD, MS, MA**[g]

[a]Division of Cardiology, Department of Medicine & Cambia Palliative Care Center of Excellence, University of Washington, Seattle, Washington, USA;

[b]Division of Cardiology, Department of Medicine, University of Washington, Seattle, Washington, USA;

[c]Department of Biostatistics, University of Washington, Seattle, Washington, USA;

[d]Division of Cardiology and Department of Global Health, University of Washington, Seattle, Washington, USA;

[e]Center for Clinical and Translational Research, Seattle Children's Research Institute, Seattle, Washington, USA;

[f]Division of Pulmonary, Critical Care and Sleep Medicine, Department of Medicine & Cambia Palliative Care Center of Excellence, University of Washington, Harborview Medical Center, Seattle, Washington, USA;

[g]Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute & Department of Pediatrics, Harvard Medical School, Boston, Massachusetts, USA.

Abstract

BACKGROUND—Adult congenital heart disease (ACHD) can negatively impact quality of life (QOL). Strengthening resilience may improve this and other psychosocial outcomes important for living a meaningful life.

OBJECTIVES—The purpose of this study was to describe resilience and key psychosocial health outcomes in ACHD and evaluate the associations between resilience and these outcomes.

METHODS—We conducted a prospective cohort study of outpatients with moderate or complex ACHD between May 2021 and June 2022. Participants completed surveys at baseline and 3 months, evaluating resilience (Connor-Davidson Resilience Scale-10), health-related QOL

This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

ADDRESS FOR CORRESPONDENCE: Dr Jill M. Steiner, University of Washington Medical Center, 1959 NE Pacific Street, HSB C502, Box 356422, Division of Cardiology, Seattle, Washington 98195, USA. jills8@uw.edu.

APPENDIX For a supplemental figure, please see the online version of this paper.

The authors attest they are in compliance with human studies committees and animal welfare regulations of the authors' institutions and Food and Drug Administration guidelines, including patient consent where appropriate. For more information, visit the Author Center.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

(EQ5D-3L, linear analog scale), health status (Euroqol visual analog scale), self-competence (Perceived Competence Scale), and psychological symptom burden (Hospital Anxiety and Depression Scale) and distress (Kessler-6).

RESULTS—The mean participant age (N = 138) was 41 ± 14 years, 51% were female, and 83% self-identified as non-Hispanic White. ACHD was moderate for 75%; 57% were physiologic class B. Mean baseline resilience score (Connor-Davidson Resilience Scale-10) was 29.20 ± 7.54. Participants had relatively good health-related QOL, health status, and self-competence, and low psychological symptom burden and distress. Higher baseline resilience was associated with better values of all outcomes at 3 months (eg, 1 point higher resilience was associated with 0.92 higher linear analog scale; 95% CI: 0.52–1.32) with or without adjustment for demographics. After further adjusting for the baseline psychosocial measure, only the association between resilience and QOL measures at 3 months remained statistically significant.

CONCLUSIONS—Resilience is positively associated with health-related QOL for outpatients with moderate or complex ACHD, though relationships are small in magnitude. Study findings can guide the application of resilience-building interventions to the ACHD population.

Keywords

resilience; congenital heart disease; quality of life; well-being; mental health

People with adult congenital heart disease (ACHD) face a range of difficult experiences across their lives, with great potential for an impaired sense of well-being.[1] Learning to balance the building of a meaningful life against the stress of worsening disease and uncertain futures often puts at risk important psychosocial outcomes like quality of life (QOL). Resilience is the process of harnessing personal resources to sustain physical and emotional well-being in the face of stress.[2,3] It can help patients navigate serious illness: when a challenge arises, people use their resilience to move beyond the challenge, alleviating stress. Resilience can be strengthened with experience and practice and alter later health outcomes.

Prior studies suggest that people with ACHD want help coping with challenges and navigating health care decisions.[4,5] How best to recognize and address these needs has moved to the forefront of both clinical and research priorities,[6] with recognition that little is known about how patients manage ACHD-related stress or how clinicians can provide needed support.

Among people with ACHD, patient-reported resilience is associated with patient-reported well-being.[7] Helping patients learn to recognize and develop resilience is a potential avenue for improving their psychosocial outcomes, and a more comprehensive understanding of resilience and well-being is necessary to engage in resilience intervention studies. The aims of this study were to use a cohort from a large academic ACHD center to describe: 1) the association between resilience and demographic characteristics; 2) the average 3-month change in resilience and psychosocial health outcomes; and 3) the association between resilience and psychosocial health outcomes. We hypothesized that people with more severe ACHD would have higher resilience and that higher levels of baseline resilience would be

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

associated with higher health-related QOL, health status, and self-competence, and lower psychological symptom burden and distress at 3 months.

METHODS

PARTICIPANTS AND PROCEDURES.

We conducted a prospective cohort study of patients who received outpatient care at a large academic ACHD center (Central Illustration). ACHD clinic appointment lists were used to identify potential participants, and recruitment occurred between May 2021 and June 2022. Eligible patients were at least 18 years of age with confirmed moderate or severe ACHD, physiologic class B, C, or D.[8] We excluded simple lesions and class A physiology to specifically evaluate those most likely to feel impacted by their ACHD. Patients with another life-limiting illness or who were unable to complete surveys independently and in English were excluded.

All eligible patients were approached for possible enrollment. If in-person at the appointment, written informed consent was provided. If contacted by phone or email afterward, verbal or written informed consent was provided. Participants then completed the baseline survey electronically. We did not collect any information, including demographics, from those who chose not to enroll.

After 3 months ±10 days, participants were asked to complete the follow-up survey via the same avenues. At each time point, up to 5 attempts (combination of phone and email) were made to encourage survey completion, unless participants opted out of further contact. To encourage participation by patients in underrepresented groups, the primary investigator (as opposed to the research coordinator) made the final attempt to contact participants with outstanding surveys. This study was approved by the University of Washington Institutional Review Board.

STUDY MEASURES.

The study survey was composed of 6 validated tools for assessing patient-centered psychosocial outcomes. Baseline and 3-month surveys were identical except that demographic information was collected only at baseline.

Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC 10),[9] a 10-item measurement of self-perceived resilience derived from an original 25-item tool. Questions evaluate personal problem-solving styles and approaches to adversity. Each item is scored on a 5-point scale (0–4), with an overall range of 0 to 40 points. Higher scores indicate higher self-perceived resilience; the mean score of a national random sample of U.S. adults was 32 ± 6.[9] CD-RISC has demonstrated responsiveness to interventions,[10,11] suggesting it can measure changes in self-perceptions and resilience resources over time.

Health-related QOL was evaluated using the EQ5D and a linear analog scale (LAS); health status was evaluated using the Euroqol visual analog scale (EQ-VAS).[12,13] The EQ5D-3L is a 5-item tool used to assess health-related QOL based on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item is scored 1 to 3; higher scores indicate

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

worse limitations. Scores yield a 5-digit number describing state of health (eg, 11111), which is indexed to represent country-specific values (iEQ5D-3L, reported), where 0 is death and 1 is full health. The tool also includes a question about health status, assessed on a 0 to 100 continuous scale (EQ-VAS). Higher scores indicate better self-perceived health. The LAS is scored on a continuous 0 to 100 scale. Higher scores indicate better self-perceived health-related QOL.

Psychological symptom burden and distress were evaluated using the Hospital Anxiety and Depression Scale (HADS)[14] and the Kessler-6 Psychological Distress Scale (K6).[15] The HADS is a 14-item tool assessing symptoms related to anxiety and depression. An adapted version of this tool was used in this study. There are 7 items each addressing anxiety and depression, scored on a 4-point scale (0–3). Scores for each subscale range from 0 to 21, with higher scores indicating higher symptom severity: 0 to 7 “normal,” 8 to 10 “mild,” 11 to 14 “moderate,” 15 to 21 “severe” burden. The K6 is a 6-item inventory measuring psychological distress. Symptoms are rated on a 5-point scale (0–4), with an overall range of 0 to 24 points. Higher scores reflect greater distress: >6 “high” distress, >12 “serious” distress.

Self-perceived competence to manage a chronic health condition (in this case, ACHD) was evaluated using the Perceived Competence Scale.[16] This is a 4-item tool; each item consists of a 7-point scale (0–6), with a total range of 0 to 24 points. Overall score is an average of responses; the maximum score is 6. Higher scores indicate greater perceived competence.

Participants were also asked to provide demographic and clinical information including marital and educational status, race and ethnicity, and whether they had been hospitalized for a heart problem in the past year. Study personnel abstracted additional baseline demographic and health data from the electronic health record, including age, gender, insurance status, ACHD diagnosis and severity,[17] year of the most recent surgery, and whether they carried a diagnosis of heart failure.

DATA ANALYSIS.

We summarized continuous variables using mean ± SD and categorical variables using proportions. There was <10% missing data for all variables of interest. To describe the association between resilience and demographic characteristics, we fit separate simple linear regression models with baseline resilience as the response and each demographic characteristic as the predictor. To evaluate the 3-month change in resilience and psychosocial health measures (EQ5D-3L, LAS, EQ-VAS, HADS, and K6), we used paired *t*-tests. To evaluate the association between resilience and psychosocial health measures, we fit 3 separate linear regression models with baseline resilience as the predictor and each psychosocial health measure at 3 months as the outcome: 1) unadjusted; 2) adjusted for age (continuous), gender (male or female), race/ethnicity (White vs non-White given small numbers), ACHD anatomic severity (moderate or complex), and marital status (single, married, partnered, other); and 3) adjusted for the variables in model 2 plus the baseline psychosocial health measure. The third model is equivalent to evaluating the association between resilience and 3-month change in psychosocial health, adjusted for baseline psychosocial health. We also conducted sensitivity analyses: 1) additionally adjusting

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

for education; 2) using ungrouped versus grouped demographic variables (race/ethnicity collapsed to non-Hispanic White vs otherwise, marital status to married/partnered vs not); 3) excluding all participants with missing data in any variable of interest (complete case analysis); and 4) using robust standard errors. Results were similar in sensitivity analyses. Data were managed using REDcap. Statistical evaluation was performed using Stata (StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC).

RESULTS

SAMPLE DESCRIPTION.

We screened 916 patients, of whom 456 (50%) met inclusion criteria. Of those invited, 6 declined, and 280 did not respond. We enrolled 170 patients; the baseline survey was completed by 150 (88%), and 138 of those (92%) also completed the 3-month survey (Supplemental Figure 1). Patients who enrolled but did not complete any surveys (N = 20) were a mean age of 37 ± 13 years, 60% were female, 60% had moderate ACHD, and 50% were physiologic class B; race, ethnicity, and marital status data are not available for this group. Participants who completed the baseline survey only (N = 12) were a mean age of 37 ± 13 years, 50% were female, 25% were married or partnered, 100% were non-Hispanic White, 25% had moderate ACHD, and 50% were physiologic class B. Among participants who completed surveys at both time points (N = 138) (Table 1), the mean age was 41 ± 14 years, 51% were female, 69% were married or partnered, and 83% were non-Hispanic White. ACHD was moderate in 75% and complex in 25%; 57% were physiologic class B, 40% class C, and 3% class D. The remainder of the manuscript reports data for this group (with baseline and 3-month assessment, N = 138) only.

ASSOCIATION BETWEEN RESILIENCE AND DEMOGRAPHIC CHARACTERISTICS.

The mean resilience score at baseline was 29.20 ± 7.54. Patients who completed education beyond high school had higher baseline resilience when compared to those who completed high school or less (Table 2). When examined as a continuous variable, each year of increased age was associated with a 0.10 higher baseline resilience score (95% CI: 0.01–0.19; $P = 0.025$), however when dichotomized to ≥40 years, this relationship was not apparent (Table 2). Patients with moderate ACHD lesions had higher resilience than those with complex lesions. There was no significant association between baseline resilience and ACHD physiologic class, heart failure diagnosis, or having been hospitalized for heart disease in the last year.

3-MONTH CHANGE IN RESILIENCE AND HEALTH OUTCOMES.

The resilience score at 3 months was similar to baseline (Table 3), with a mean resilience change of −0.30 ± 7.26 over 3 months. Overall, patients had relatively good health-related QOL and health status, low psychological symptom burden and distress, and good self-competence based on mean scores at baseline and 3 months (Table 3). Baseline EQ5D-3L score was “11111,” meaning “full health,” for 30% of patients. Of all the psychosocial health outcomes, only the score for the HADS-Anxiety subscale was statistically different at

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

3 months compared to baseline (baseline 6.10 ± 3.93 vs 3 months 5.62 ± 3.76, paired *t*-test $P = 0.02$).

ASSOCIATION BETWEEN RESILIENCE AND HEALTH OUTCOMES.

In unadjusted models, baseline resilience was significantly associated with all outcomes at 3 months (Table 4). For example, a 1-point higher resilience was associated with 0.92 higher LAS (95% CI: 0.52–1.32; $P < 0.001$). After adjusting for age, gender, race/ethnicity, ACHD anatomic severity, and marital status, baseline resilience remained significantly associated with all outcomes. However, after further adjusting for the baseline psychosocial measure, only the association between resilience and QOL measures at 3 months (or equivalently, change in 3 months) remained statistically significant: for each 1-point higher CD-RISC 10 score at baseline, there was a 0.004-point higher iEQ5D-3L score 3 months later (95% CI: 0.001–0.007; $P = 0.004$) and a 0.38-point higher LAS score 3 months later (95% CI: 0.05–0.72; $P = 0.03$) among participants with the same baseline value of the outcome and other covariates.

DISCUSSION

To better understand the psychosocial impacts of living with ACHD, we described the degree and stability of resilience and key psychosocial health outcomes, as well as associations between them, over a 3-month period. In general, participants reported good health-related QOL, health status, and self-competence, and low psychological symptom burden and distress. Higher baseline resilience was associated with better values of all outcomes at 3 months, with or without adjustment for demographics. After further adjusting for the baseline psychosocial measure, only the association between resilience and QOL measures at 3 months remained statistically significant. Although other studies have investigated some of these health outcomes in ACHD, they have not been examined in relation to resilience or in a longitudinal fashion. Knowledge of these relationships will assist in the development of interventions intended to improve psychosocial health in ACHD.

Patients demonstrated CD-RISC10 resilience scores that were lower on average than the reported mean for a random sample of U.S. adults,[18] but on par with other chronic disease groups, such as people with neurological disabilities[19] and HIV positive women.[20] Recently, Gmuca et al[21] reported a score of 25 ± 8.8 in adolescents and young adults with chronic pain. In other ACHD studies, patients have been found to have moderately low to moderate resilience levels, as measured with the Resilience Scale.[22,23] We anticipated finding higher resilience in patients with worse ACHD, suspecting they faced more prior health challenges. However, we did not identify significant differences in patients with markers of worse physiologic impact such as class C or D disease, heart failure diagnosis, or a recent hospitalization or surgery. In contrast, in an earlier cross-sectional study,[24] patients with NYHA functional class II versus I symptoms reported worse resilience, but there was no association with ACHD diagnosis, and the relationship between resilience and QOL was not evaluated. In our study, scores were higher in patients with moderate as compared to complex lesions, and we wonder whether this reflects the temporality of living with ACHD.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

For example, a patient with stable complex ACHD may reflect restrictions during their early or teenage lives when they had less control and were ill-equipped to cope with their illness and the resulting impacts on their adult[25] or illness identity.[26] It is also possible that demographic differences between those with moderate and complex ACHD influenced these findings: those with moderate ACHD were older and more likely to be married or partnered.

Beyond ACHD severity, we saw some differences in resilience by sociodemographic characteristics. Lower resilience was reported by patients with less than a high school education. We also saw trends toward lower resilience in patients who were not married or partnered or who self-identified as belonging to underrepresented racial/ethnic or gender groups. This suggests the additional impact of social inequities in this population, signaling the need for additional studies[27] designed to specifically evaluate these associations, ideally in adequately sized and representative samples.

Patients in our study scored similarly on the LAS, HADS-A, and HADS-D as compared to the international APPROACH-IS study.[28] They scored roughly 5 to 7 points lower on the EQ-VAS reported there and also in a Swedish study by Berghammer et al[29] below the minimally important change suggested for this instrument in other populations.[30,31] Indexed EQ5D-3L scores were similar to those reported by Berghammer, even though fewer patients in our sample reported full health. Therefore, our population did not seem atypical from other groups of studied patients with ACHD. Our findings build on theirs as both prior studies were cross sectional, had limited or no U.S. representation, and neither measured resilience.

Our study is the first to describe these psychosocial properties in ACHD using a longitudinal observational design. Knowledge of whether and when resilience or these key outcomes change can guide intervention development, both in terms of intervention timing and outcomes measurement. We chose to evaluate a 3-month period because it reflects the length of some behavioral interventions, including one of interest to our research.[3] It is also the period over which one would practice a skill to build a habit, as well as the length of the most intense period following an adverse event. While additional studies should evaluate long-term stability or the effects of health-related events, the relatively small mean changes demonstrated for the majority of these health outcomes in this study adds to knowledge both about this population's psychosocial health and the performance of these measures in this population.

Since patients manage acute health challenges using whatever resilience has been developed prior to that point,[32,33] we were interested to know how baseline resilience was related to 3-month psychosocial health outcomes. For example, a patient with ACHD who has a cardiac arrest will draw on already present resilience resources to manage distress or anxiety, not having had time to build new resilience prior to an unexpected event. In this study, associations between resilience and health outcomes were in the expected direction (eg, higher resilience associated with better outcomes) and associations with QOL were statistically significant. This is in line with findings from a cross-sectional study of healthy children and adults with repaired tetralogy of Fallot that found resilience to be positively associated with QOL.[34] However, associations found in our study were small and unlikely

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

to be clinically meaningful. The minimal clinically important difference of the EQ5D-3L has not been studied in ACHD and is reported to be 0.028 or higher in other populations.[35,36] Additionally, we did not see significant relationships between resilience and the other health outcomes in adjusted models. These findings raised questions of whether we had chosen the correct outcomes or the best tools to measure those outcomes in relation to resilience.

It is also possible that this relatively healthy group of outpatients is not the most appropriate population in which to study these relationships. To effectively promote better psychosocial care, clinicians must reach the patients who need support the most, those who are experiencing significant stress and also have trouble managing it. Even during an obvious clinical change or event, it can be difficult to tell who these patients are or when is the best time to intervene. It can also be challenging for patients to learn new coping skills or remember to use practiced skills in times of stress. Experience with these concerns is minimal in ACHD, constrained at least partially by a lack of population-level data and accessibility limitations imposed by insurance coverage and specialist availability. The relationships between resilience and these key psychosocial outcomes may be more evident in patients experiencing more disease-related distress or uncertainty.

STUDY LIMITATIONS.

This study has some important limitations. Although conducted at a large ACHD referral center that provides care to a 5-state region, our results reflect the subset of this population that was able to travel to and afford care at our center. It is encouraging that scores for many of the health outcomes were similar to prior studies; however, results may not be generalizable to the broader population or those eligible patients who declined participation. Some demographic categories and some clinical categories like class D disease had small numbers, and in some of these smaller groups we saw nonsignificant differences in resilience scores. Collapsing variables in sensitivity analyses did not substantially change results; however, it is possible that we may have demonstrated significant relationships with a larger sample. Additionally, any clinical events occurring during the study period could have affected 3-month responses, however, given the overall stability observed in the variables assessed, this is unlikely to have influenced the main findings of this study. Finally, it is possible that the COVID pandemic may have impacted survey results given its recognized impact on mental health.[37] Data collection occurred after the end of most mandatory restrictions, though the omicron variant was still prevalent.

CONCLUSIONS

Resilience and person-centered psychosocial outcomes are relatively unchanged over a 3-month period for outpatients with moderate or complex ACHD, and resilience is positively associated with health-related QOL. These findings can guide the application of resilience-building interventions to the ACHD population, with the goal of improving psychosocial well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

FUNDING SUPPORT AND AUTHOR DISCLOSURES

This work was supported by NIH/NHLBI (K23HL15180 [to Dr Steiner]). REDCap is supported by the UW Institute of Translational Health Sciences, funded by UL1TR002319, National Center for Advancing Translational Sciences, National Institutes of Health. The authors have reported that they have no relationships relevant to the contents of this paper to disclose.

ABBREVIATIONS AND ACRONYMS

ACHD	adult congenital heart disease
CD-RISC 10	Connor-Davidson Resilience Scale
EQ-VAS	Euroqol visual analog scale
HADS	Hospital Anxiety and Depression Scale
K6	Kessler-6 Psychological Distress Scale
LAS	linear analog scale
QOL	quality of life

REFERENCES

1. Kovacs AH, Brouillette J, Ibeziako P, et al. Psychological outcomes and interventions for Individuals with congenital heart disease: a scientific statement from the American heart association. Circ Cardiovasc Qual Outcomes. 2022;15(8):1–17.
2. Luthar SS, Cicchetti D, Becker B. The Construct of resilience: a critical evaluation and guidelines for future work. Child Dev. 2000;71(3):543–562. [PubMed: 10953923]
3. Rosenberg AR, Bradford MC, Junkins CC, et al. Effect of the promoting resilience in stress Management intervention for Parents of children with cancer (PRISM-P): a randomized clinical trial. JAMA Netw Open. 2019;2(9):e1911578. [PubMed: 31532518]
4. Pagé MG, Kovacs AH, Irvine J. How do psychosocial challenges associated with living with congenital heart disease translate into treatment interests and preferences? A qualitative approach. Psychol Health. 2012;27(11):1260–1270. [PubMed: 22433017]
5. Kovacs AH, Moons P. Psychosocial Functioning and quality of life in adults with congenital heart disease and heart failure. Heart Fail Clin. 2014;10(1):35–42. [PubMed: 24275293]
6. Drury NE, Herd CP, Biglino G, et al. Research priorities in children and adults with congenital heart disease: a James Lind Alliance priority Setting partnership. Open Hear. 2022;9(2): e002147.
7. Chow P-C. Quality of life, psychological resilience, personality traits and illness perception in grown-up congenital heart patients in Hong Kong. Int J Cardiol Congenit Hear Dis. 2021;6:100279.
8. Stout KK, Committee W, Daniels CJ, et al. 2018 AHA/ACC guideline for the management of adults with congenital heart disease. J Am Coll Cardiol. 2018;139:e698–e800.
9. The Connor-Davidson resilience scale (CD-RISC): Home. Accessed April 28, 2019. http://www.connordavidson-resiliencescale.com/
10. Friedman K, Marenus MW, Murray A, et al. Enhancing physical activity and psychological well-being in College Students during COVID-19 through WeActive and WeMindful interventions. Int J Environ Res Public Health. 2022;19(7):4144. [PubMed: 35409827]
11. Rosenberg AR, Bradford MC, McCauley E, et al. Promoting resilience in adolescents and young adults with cancer: results from the PRISM randomized controlled trial. Cancer. 2018;124(19): 3909–3917. [PubMed: 30230531]
12. EuroQOL instruments. Accessed March 22, 2021. https://euroqol.org/eq-5d-instruments/

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

13. Apers S, Kovacs AH, Luyckx K, et al. Assessment of patterns of patient-reported outcomes in adults with congenital heart disease - international study (APPROACH-IS): rationale, design, and methods. Int J Cardiol. 2015;179(20130607): 334–342. [PubMed: 25464481]
14. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. J Psychosom Res. 2002;52(2):69–77. [PubMed: 11832252]
15. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psychol Med. 2002;32(6):959–976. http://www.ncbi.nlm.nih.gov/pubmed/12214795 [PubMed: 12214795]
16. Self-determination theory Questionnaires. Accessed May 6, 2019. http://selfdeterminationtheory.org/questionnaires/
17. Stout KK, Daniels CJ, Chair V, et al. 2018 AHA/ACC Guideline for the Management of adults with congenital heart disease. Circulation. 2019;139: e698–e800. [PubMed: 30586767]
18. Campbell-Sills L, Forde DR, Stein MB. Demographic and childhood environmental predictors of resilience in a community sample. J Psychiatr Res. 2009;43(12):1007–1012. [PubMed: 19264325]
19. Battalio S, Silverman A, Ehde D, Edwards K, Jensen M. Resilience and Function in adults with physical disabilities: an observational study. Arch Phys Med Rehabil. 2016;98(6):1158–1164. [PubMed: 27993585]
20. Dale S, Cohen M, Weber K, Cruise R, Kelso G, Brody L. Abuse and resilience in relation to HAART medication adherence and HIV viral load among women with HIV in the United States. AIDS Patient Care STDS. 2014;28(3):136–143. [PubMed: 24568654]
21. Gmuca S, Weiss P, McGill M, et al. The Feasibility and Acceptability of resilience Coaching for adolescent chronic Musculoskeletal pain: a single-Arm Pilot trial. Children. 2022;9(10):1432. [PubMed: 36291374]
22. Kovacs AH, Grace SL, Kentner AC, Nolan RP, Silversides CK, Irvine MJ. Feasibility and outcomes in a Pilot randomized controlled trial of a psychosocial intervention for adults with congenital heart disease. Can J Cardiol. 2018;34(6):766–773. [PubMed: 29801741]
23. Lee S, Lee J, Choi JY. The effect of a resilience improvement program for adolescents with complex congenital heart disease. Eur J Cardiovasc Nurs. 2017;16(4):290–298. [PubMed: 27400701]
24. Bang JS, Jo S, Kim GB, et al. The mental health and quality of life of adult patients with congenital heart disease. Int J Cardiol. 2013;170(1):49–53. [PubMed: 24139784]
25. Steiner JM, Dhami A, Brown CE, et al. It's part of who I am: the impact of congenital heart disease on adult identity and life experience. Int J Cardiol Congenit Hear Dis. 2021;4:100146.
26. Van Bulck LV, Goossens E, Luyckx K, Oris L, Apers S, Moons P. Illness identity: a novel predictor for healthcare use in adults with congenital heart disease. J Am Heart Assoc. 2018;7(11):1–12.
27. Lopez KN, Baker-Smith C, Flores G, et al. Addressing social Determinants of health and Mitigating health disparities across the Lifespan in congenital heart disease: a Scientific Statement from the American heart association. J Am Heart Assoc. 2022;11(8):1–21.
28. Moons P, Kovacs AH, Luyckx K, et al. Patient-reported outcomes in adults with congenital heart disease: Inter-country variation, standard of living and healthcare system factors. Int J Cardiol. 2018;251:34–41. [PubMed: 29107358]
29. Berghammer M, Karlsson J, Ekman I, Eriksson P, Dellborg M. Self-reported health status (EQ-5D) in adults with congenital heart disease. Int J Cardiol. 2013;165(3):537–543. [PubMed: 22051437]
30. Joelson A, Nerelius F, Sigmundsson FG, Karlsson J. The minimal important change for the EQ VAS based on the SF-36 health transition item: observations from 25772 spine surgery procedures. Qual Life Res. 2022;31(12):3459–3466. [PubMed: 35821173]
31. Zanini A, Aiello M, Adamo D, et al. Estimation of minimal clinically important difference in EQ-5D visual analog scale score after pulmonary rehabilitation in subjects with COPD. Respir Care. 2015;60(1):88–95. [PubMed: 25336531]
32. Rosenberg AR, Brown CE, Rosa WE, Yi-Frazier JP. When resilience is cliche and resilience resources are taboo: how language and policies exacerbate mental health disparities. Lancet Child Adolesc Health. 2023;7(4):236–237. [PubMed: 36646095]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

33. Rosenberg AR, Yi-Frazier JP. Commentary: resilience defined: an alternative perspective. J Pediatr Psychol. 2016;41(5):506–509. [PubMed: 27013701]

34. Frigiola A, Bull C, Wray J. Exercise capacity, quality of life, and resilience after repair of tetralogy of Fallot: a cross-sectional study of patients operated between 1964 and 2009. Cardiol Young. 2014;24(1):79–86. [PubMed: 23414679]

35. Bae E, Choi SE, Lee H, Shin G, Kang D. Validity of EQ-5D utility index and minimal clinically important difference estimation among patients with chronic obstructive pulmonary disease. BMC Pulm Med. 2020;20(1):1–10. [PubMed: 31900129]

36. Yapp LZ, Scott CEH, Howie CR, MacDonald DJ, Simpson AHRW, Clement ND. Meaningful values of the EQ-5D3L in patients undergoing primary knee arthroplasty. Bone Jt Res. 2022;11(9):619–628.

37. Steiner JM, Corage Baden A, Abu-Rish Blakeney E, et al. COVID-19 impact on adults with congenital heart disease self-perceived vulnerability and coping. Eur J Cardiovasc Nurs. 2022;21(8):868–872. [PubMed: 35670151]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

PERSPECTIVES

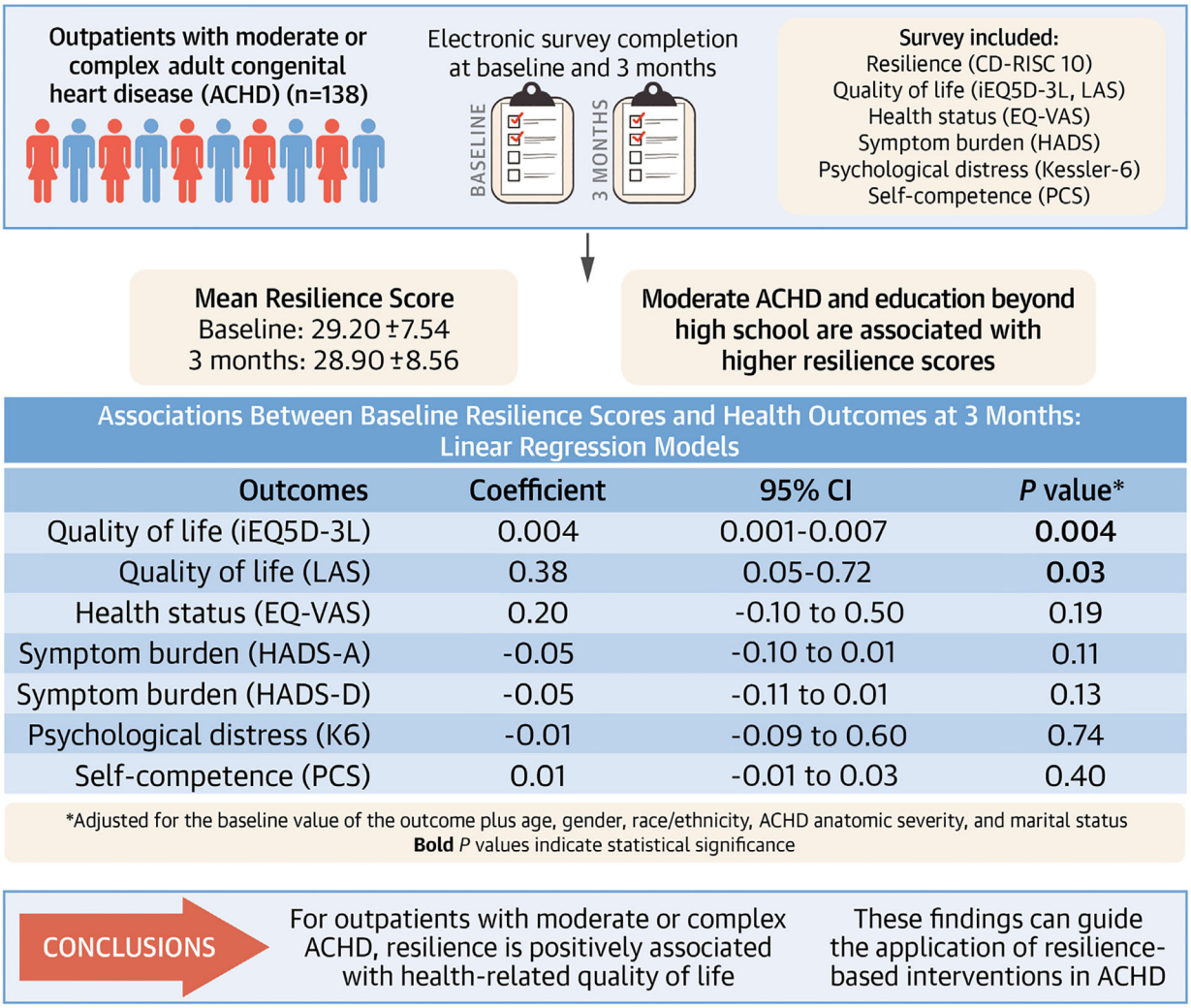
COMPETENCY IN MEDICAL KNOWLEDGE:

In this longitudinal survey study of patients with ACHD, we describe key psychosocial health factors and demonstrate relative stability of these factors over a 3-month period. We also describe relationships between resilience and these factors, specifically that resilience is positively associated with health-related QOL. These findings can guide the application of resilience-building interventions to the ACHD population, with the goal of improving psychosocial well-being.

TRANSLATIONAL OUTLOOK:

Management of psychosocial health is an important part of whole-person ACHD care. Clinicians should incorporate psychosocial assessment into routine care, and future research should contribute to a more comprehensive understanding of psychosocial health influences. Resilience development is a potential avenue for supporting improved psychosocial and mental health outcomes in ACHD.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript



Associations Between Baseline Resilience Scores and Health Outcomes at 3 Months: Linear Regression Models

Outcomes	Coefficient	95% CI	*P* value*
Quality of life (iEQ5D-3L)	0.004	0.001-0.007	**0.004**
Quality of life (LAS)	0.38	0.05-0.72	**0.03**
Health status (EQ-VAS)	0.20	-0.10 to 0.50	0.19
Symptom burden (HADS-A)	-0.05	-0.10 to 0.01	0.11
Symptom burden (HADS-D)	-0.05	-0.11 to 0.01	0.13
Psychological distress (K6)	-0.01	-0.09 to 0.60	0.74
Self-competence (PCS)	0.01	-0.01 to 0.03	0.40

*Adjusted for the baseline value of the outcome plus age, gender, race/ethnicity, ACHD anatomic severity, and marital status
Bold *P* values indicate statistical significance

CENTRAL ILLUSTRATION.
Resilience and Key Psychological Health Outcomes in ACHD: Design and Primary Findings

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

TABLE 1

Participant Demographics (N = 138)

Age, y	41 ± 14
Sex	
Female	71 (51)
Male	66 (48)
Transgender	1 (1)
Marital status	
Single	34 (25)
Married	76 (55)
Partnered	19 (14)
Divorced/separated	6 (4)
Widowed	2 (1)
Not reported	1 (1)
Race/ethnicity	
White	114 (83)
Black	4 (3)
Asian	7 (5)
Hispanic/Latino	6 (4)
AIAN	1 (1)
Other	4 (3)
Not reported	2 (1)
Education	
≤8th grade	1 (1)
High school or equivalent	34 (25)
4-y college degree	57 (41)
Graduate degree	34 (25)
Other	11 (8)
Not reported	1 (1)
Insurance	
Public	26 (19)
Private	106 (77)
Other	2 (1)
None	4 (3)
ACHD lesion	
Moderate	103 (75)
Complex	35 (25)
ACHD phys	
B	79 (57)
C	55 (40)
D	4 (3)
HF diagnosis	39 (28)

Hospitalized in last year	36 (26)

Values are mean ± SD or n (%).

ACHD = adult congenital heart disease; AIAN = American Indian or Alaska Native; HF = heart failure.

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

TABLE 2

Baseline Resilience Scores Across Key Demographic Groups[a]

	N (%)	Baseline CDRISC10 Score	*P* Value
Age			0.14
<40 y	76 (55)	28.34 ± 7.04	
≥40 y	62 (45)	30.24 ± 8.04	
Gender (n = 137)			0.24
Female	71 (52)	28.51 ± 8.39	
Male	66 (48)	30.03 ± 6.49	
Marital status (n = 129)			0.06
Single	34 (26)	27.24 ± 7.12	
Married/Partnered	95 (74)	29.97 ± 7.40	
Race/Ethnicity (n = 136)			0.14
White	114 (84)	29.52 ± 7.60	
Non-White	22 (16)	26.91 ± 6.91	
Education (n = 126)			**0.02**
High school or less	35 (28)	26.83 ± 7.49	
Beyond high school	91 (72)	30.31 ± 7.27	
Insurance (n = 132)			0.72
Public	26 (20)	28.81 ± 8.04	
Private	106 (80)	29.41 ± 7.56	
ACHD lesion			**0.01**
Moderate	103 (75)	30.11 ± 7.39	
Complex	35 (25)	26.51 ± 7.43	
ACHD physiology			
B	79 (57)	29.34 ± 7.55	(cons)
C	55 (40)	28.69 ± 9.83	0.62
D	4 (3)	33.25 ± 7.74	0.32
Last surgery			0.77
<5 years ago	65	29.40 ± 7.88	
>5 years ago	73	29.01 ± 7.27	
Heart failure diagnosis			0.10
No	99 (72)	29.86 ± 6.82	
Yes	39 (28)	27.51 ± 8.99	
Hospitalized in last year			0.59
No	102 (74)	29.40 ± 7.75	
Yes	36 (26)	28.61 ± 6.97	

Values are n (%) or mean ± SD.

[a]N = 138 unless otherwise specified.

The **bold** *P* values indicate statistical significance.

ACHD = adult congenital heart disease; CD-RISC 10 = Connor-Davidson Resilience Scale-10.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

TABLE 3

Mean Scores for Resilience and Health Outcomes at Baseline and 3 Months

Tool[a]	Baseline	3-Month	Change	*P* Value
Resilience (CD-RISC 10, n = 138)	29.20 ± 7.54	28.90 ± 8.56	−0.30 ± 7.26	0.63
Quality of life (indexed Eq5D-3L, n = 137)	0.85 ± 0.14	0.85 ± 0.16	−0.003 ± 0.12	0.77
Quality of life (LAS, n = 129)	78.19 ± 17.42	78.12 ± 18.69	−0.06 ± 13.67	0.96
Health status (EQ-VAS, n = 137)	72.95 ± 15.95	74.30 ± 16.21	1.35 ± 13.06	0.23
Symptom burden (HADS-Anxiety Subscale, n = 138)	6.10 ± 3.93	5.62 ± 3.76	−0.48 ± 2.29	**0.02**
Symptom burden (HADS-Depression Subscale, n = 138)	3.93 ± 3.37	3.96 ± 3.54	0.03 ± 2.19	0.88
Psychological distress (K6, n = 138)	5.16 ± 4.29	5.43 ± 4.81	0.27 ± 2.60	0.23
Self-competence (PCS, n = 134)	5.00 ± 1.04	5.01 ± 1.12	0.01 ± 0.82	0.88

Values are mean ± SD.

[a]Max scores: EQ5D-3L (1), LAS (100), EQ-VAS (100), HADS-A (21, <8 normal), HADS-D (21, <8 normal), K6 (24, >6 “high distress”), PCS (6).

The **bold** *P* values indicate statistical significance.

CD-RISC 10 = Connor-Davidson Resilience Scale-10; EQ-VAS = Euroqol visual analog scale; HADS = Hospital Anxiety and Depression Scale; K6 = Kessler-6 Psychological Distress Scale; LAS = linear analog scale; PCS = Perceived Competence Scale.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

TABLE 4

Associations Between Baseline Resilience and Health Outcomes at 3 Months

	Unadjusted				Partially Adjusted[a]				Fully Adjusted[b]			
	N	**Coeff**	**95% CI**	***P* Value**	**N**	**Coeff**	**95% CI**	***P* Value**	**N**	**Coeff**	**95% CI**	***P* Value**
Quality of life (iEq5D-3L)	137	0.008	0.004–0.01	<**0.001**	133	0.008	0.004–0.01	<**0.001**	133	0.004	0.001–0.007	**0.004**
Quality of life (LAS)	132	0.92	0.52–1.32	<**0.001**	128	0.96	0.52–1.39	<**0.001**	125	0.38	0.05–0.72	**0.03**
Health status (EQ VAS)	138	0.54	0.19–0.90	**0.003**	134	0.57	0.20–0.95	**0.003**	133	0.20	−0.10 to 0.50	0.19
Symptom burden (HADS-A)	138	−0.23	−0.30 to −0.15	<**0.001**	134	−0.21	−0.29 to −0.12	<**0.001**	134	−0.05	−0.10 to 0.01	0.11
Symptom burden (HADS-D)	138	−0.23	−0.30 to −0.16	<**0.001**	134	−0.24	−0.32 to −0.17	<**0.001**	134	−0.05	−0.11 to 0.01	0.13
Psychological distress (K6)	138	−0.32	−0.42 to −0.23	<**0.001**	134	−0.30	−0.40 to −0.20	<**0.001**	134	−0.01	−0.09 to 0.06	0.74
Self-competence (PCS)	136	0.06	0.04–0.08	<**0.001**	132	0.06	0.31–0.83	<**0.001**	130	0.01	−0.01 to 0.03	0.40

[a]Partially adjusted accounts for age, gender, race/ethnicity, ACHD anatomic severity, and marital status.

[b]Fully adjusted accounts for the baseline value of the outcome in addition to partially adjusted.

BOLD = statistically significant; EQ-VAS = Euroqol visual analog scale; HADS = Hospital Anxiety and Depression Scale; K6 = Kessler-6 Psychological Distress Scale; LAS = linear analog scale; PCS = Perceived Competence Scale.