



Original Article

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A pilot study of the WE BEAT Well-Being Education Programme to build resilience in adolescents with heart disease

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Abstract

Objective(s): To examine feasibility, acceptability, and preliminary effectiveness of a novel group-based telemedicine psychoeducation programme aimed at supporting psychological well-being among adolescents with Fontan-palliated CHD. **Study design:** A 5-week telemedicine psychoeducation group-based programme (WE BEAT) was developed for adolescents ($N = 20$; 13–18 years) with Fontan-palliated CHD aimed at improving resiliency and psychological well-being. Outcome measures included surveys of resilience (Connor–Davidson Resilience Scale), benefit finding (Benefit/Burden Scale for Children), depression, anxiety, peer relationships, and life satisfaction (National Institutes of Health Patient-Reported Outcomes Measurement Information System scales). Within-subject changes in these outcomes were compared pre- to post-intervention using Cohen's d effect size. In addition, acceptability in the form of satisfaction measures and qualitative feedback was assessed. **Results:** Among eligible patients reached, 68% expressed interest in study participation. Of those consented, 77% have been scheduled for a group programme to date with 87% programme completion. Twenty adolescents (*mean* age $16.1 \pm SD$ 1.6 years) participated across five WE BEAT group cohorts (range: 3–6 participants per group). The majority (80%) attended 4–5 sessions in the 5-session programme, and the median programme rating was a 9 out of 10 (10 = most favourable rating). Following WE BEAT participation, resiliency ($d = 0.44$) and perceptions of purpose in life increased ($d = 0.26$), while depressive symptoms reduced ($d = 0.36$). No other changes in assessed outcome measures were noted. **Conclusions:** These findings provide preliminary support that a group-based, telemedicine delivered psychoeducation programme to support psychological well-being among adolescents with CHD is feasible, acceptable, and effective. Future directions include examining intervention effects across diverse centres, populations, and implementation methods.

Introduction

Leading cardiovascular societies and research entities, including the American Heart Association and National Institutes of Health, have recently called for psychological intervention and implementation research to address the mental health needs of individuals living with CHD.^{1–3} Risk of mental health comorbidity in CHD is well established. When compared to children without CHD, a seven times higher risk of mental health diagnosis or treatment has been observed in complex CHD and a five times higher risk has been identified among those with simple CHD.⁴ For adolescents with complex CHD, research estimates that 65% will experience a mental health diagnosis in their lifetime.⁵

While these mental health comorbidities are increasingly being recognised, it is also important to acknowledge that many young people with CHD demonstrate resilience.^{6,7} Resilience has been defined as the process by which an individual harnesses internal, external, and learned resources to maintain well-being amidst a stressor,⁸ such as chronic or critical illness. In a recent study of 10- to 25-year-olds with CHD and healthy controls, those with CHD had higher resilience scores with higher resilience also found to be associated with absence of mental health diagnosis.⁶ Others have reported correlations between higher resilience and lower depressive symptoms in adolescents with CHD.⁹ Across adult CHD and other paediatric chronic illness groups, resilience-focused interventions have resulted in reductions in health-related anxiety,¹⁰ depression,¹¹ and psychological distress.^{12,13} Resiliency has been shown to be associated with improved health-related quality of life in paediatric cancer patients,¹³ better

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glycemic control in adolescents with diabetes,¹⁴ and more stable healthcare transitions in paediatric transplant recipients.¹⁵

The WE BEAT Well-Being Education Programme was designed to address the critical need for well-being and mental health-focused youth-directed interventions in CHD.^{1,2,16} In a recent systematic review of the literature, only four psychological interventions involving adolescents with CHD were identified and none of these interventions were associated with improved psychological functioning.¹⁶ As described previously,¹⁷ WE BEAT programme development was informed by patient-focused research and resilience theory with the goal of improving psychological well-being and resilient outcomes in individuals with paediatric heart disease. The current study aimed to examine the feasibility and acceptability of the WE BEAT Well-Being Education Programme delivered via group-based telemedicine in a sample of 20 adolescents with Fontan-palliated CHD. The secondary aim of the study was to preliminarily examine effectiveness of the WE BEAT group-based programme to inform the design and development of future, sufficiently powered, multi-site effectiveness and implementation trial. It was hypothesised that the programme would demonstrate initial feasibility, acceptability, and effectiveness.

Materials and methods

Study design

This single-centre Institutional Review Board-approved pilot intervention study utilised a within-subject design to understand programme feasibility and acceptability. The study was also registered with ClinicalTrials.gov (NCT05199857) although patients were not randomised in this pilot study design. Recruitment started in early 2022, and analysis was completed in fall 2023.

Participants and recruitment

An initial pilot sample of 20 participants was targeted for the WE BEAT programme, consistent with other published resilience intervention studies in paediatric chronic illness and adult CHD. Eligible participants included adolescents ages 13–18 years of age at enrolment with Fontan-palliated CHD who received current or historic care at the study heart centre. Participants could live anywhere in the United States, but all data were collected at study site (Midwest children's hospital). Due to the nature of the WE BEAT intervention delivery, English fluency was required for study participation, as well as access to an internet-capable electronic device for telemedicine-based group intervention. Participants with suicidal or homicidal intent or attempt within the past 6 months as determined by medical chart review or their primary cardiologist were not eligible for the pilot study in order to ensure patient and group member safety.

This pilot study was funded by a philanthropic gift which included a 2-part investigation of complementary, sequential interventions, the WE BEAT programme as described here, followed by a 6-month individualised, guided exercise programme. All WE BEAT programme surveys were completed prior to starting the subsequent exercise intervention. Pilot study enrollees did consent to participation in both sequential interventions. Due to the nature of the subsequent exercise intervention, medical exclusion criteria included the following: current intravenous inotropic drug therapy, severe ventricular dysfunction, severe valvar regurgitation, ventricular outflow obstruction, or aortic arch

obstruction within past 6 months per clinical echocardiography, and history of arrhythmia with exercise.

Recruitment fliers and notices were posted within the heart centre, distributed to centre-based and referring cardiologists, and shared on the heart centre website and parent-driven heart centre-related social media site. Research staff also reviewed weekly clinic and inpatient lists for potentially eligible participants. Recruitment and study enrollment occurred via multiple modalities, including in-person, phone, and email. Written youth assent and parent/guardian consent were obtained in person or through Health Insurance Portability and Accountability Act-compliant electronic methods.

Intervention

The development, design, and evidence-based components of the WE BEAT Well-Being Education Programme have been described in detail previously.¹⁷ In overview, it is a group-based psycho-education and coping skills training programme developed through patient/caregiver input and research, a theoretical resilience science framework, and prior intervention research. The programme is delivered by a licenced psychologist or a supervised limited licenced psychology trainee through Health Insurance Portability and Accountability Act-compliant telemedicine technology to groups of approximately 4–10 adolescents with similar heart disease diagnoses. The programme includes five weekly 45-minute sessions on the following modules: (1) Well-being Education, Introduction and Community Building; (2) Breathe, Mindfulness and Relaxation-Based Skills; (3) Energize, Positive Psychology Skills; (4) Adjust, Cognitive Skills Training; and (5) Thank, Gratitude. Each session follows a similar outline: (I) Welcome/Check-In, (II) Evidence, (III) Skill Building, and (IV) Goal Setting and Wrap-Up. Detailed description of the core programme components and modules is provided in the previously published design manuscript.¹⁷

Measures

Background measure

Parent/guardians completed a background/demographic questionnaire electronically at study enrolment which also included six items regarding patient mental health history, past/current treatment, and perceived mental health needs. All study measures were completed electronically by patient participants using the secure, Health Insurance Portability and Accountability Act-compliant REDCap data capture system. A research coordinator was available to assist with study measure completion when needed. Baseline measures were completed during Session 1 of the WE BEAT programme, and post-intervention measures were completed during Session 5 (i.e., ~5 weeks post-enrollment). In the instance a participant was not present for Sessions 1 or 5, they were sent the surveys via email to complete on their own.

Feasibility and acceptability measures

The Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework was used to guide the assessment of WE BEAT programme feasibility and acceptability. The RE-AIM framework has been widely used to guide the development, implementation, and effectiveness of behavioural health interventions. The five RE-AIM dimensions include the following: (1) Reach, (2) Effectiveness, (3) Adoption, (4) Implementation, and (5) Maintenance.^{18,19} Population reach was assessed by tracking participant eligibility/ineligibility, participant

enrolment, reasons for not enrolling/disenrolling, and analysis of demographic differences between participants and non-participants. Adoption, or acceptability, was assessed via group session attendance, participant-completed session rating/satisfaction scales, and participant-completed programmatic rating/satisfaction scale.

Study baseline, session, and post-intervention surveys were completed electronically by adolescent participants. The investigator-designed session rating scale included two items: a 0–10 rating scale (0 = poor, 10 = great) and an open-ended prompt for feedback/thoughts on session. The programme rating scale included six additional items: an overall programme 0–10 rating scale, the commonly used “would you recommend to a friend (peer with heart disease)” 0–10 programme satisfaction rating scale (0 = not at all likely to recommend, 10 = very likely to recommend), one multi-select item regarding positive programme components, and three open-ended questions soliciting feedback for improvement (i.e., what did you like/not like, what would you change) and impact of programme on participant. Implementation (i.e., cost, time, resources, centre, and clinician characteristics) were not measured in this phase of the research; however, details regarding deployment are discussed below. In this pilot phase of the study, maintenance was simply measured by percentage of participants to complete the 5-week programme.

Effectiveness measures

The primary outcome measure for preliminary programme effectiveness was the participant-completed 10-item Connor–Davidson Resilience Scale.^{20,21} Total scores range from 0 to 40 with higher scores indicating greater resilience. This measure has been used in other intervention studies targeting resilience in adolescents with cancer^{12,13} and was recently used in a larger study of resilience among children, adolescents, and young adults with CHD.⁶ Secondary measures included the participant-completed 20-item Benefit/Burden Scale for Children,²² a 5-point Likert scale used to measure benefit finding and burden of chronic illness in children aged 8–17 years old. Additionally, the following National Institutes of Health Patient-Reported Outcomes Measurement Information System scales^{23–25} were completed by participants: Depressive Symptoms (8 items), Anxiety (8 items), Peer Relationships (8 items), and Life Satisfaction (4 items). These scales have been validated for use in children and adolescents with chronic health conditions.

Analysis plan

Feasibility and acceptability

Descriptive statistics of participants’ demographics and feasibility and acceptability data were presented as frequency and percentage (%) for categorical variables, and mean \pm standard deviation or median and interquartile range, depending on distributional assumption, for continuous variables.

Preliminary effectiveness

A standardised mean difference was calculated using Cohen’s *d* effect sizes²⁶ for changes in scores from pre- to post-intervention to examine preliminary programme effectiveness on resilience measured by the Connor–Davidson Resilience Scale, benefit/burdens of illness measured by Benefit/Burden Scale for Children, and Patient-Reported Outcomes Measurement Information System scales. The magnitude of effect sizes are defined as small (approximately $d = 0.20$), medium (approximately $d = 0.50$), and

large (approximately $d = 0.80$).²⁶ Due to the small sample size, a *p* value from change in scores over time was not reported. The use of effect size only is appropriate for this study analysis as it is independent of sample size and can better capture the impact of a treatment on an outcome of interest.²⁷ It is important to recognise that even a small magnitude effect size change can be clinically meaningful for the outcome of interest (i.e., “small” improvements in psychological functioning can be very meaningful for an individual).²⁸ All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA).

Results

Participants

Figure 1 depicts participant screening, eligibility, and enrolment per CONSORT Transparent Reporting guidelines. Among 82 eligible patients, 59 were able to be contacted (72%). Of those reached by study team, 40 (68%) expressed interest in programme participation. Of the 30 participants who have consented to the study, 23 were scheduled to start a WE BEAT cohort with 20 patients completing the programme (87% completion rate). A total of 20 patients participated in the WE BEAT group pilot study through the first five group cohorts. Patient and family sociodemographic data are reported in Table 1. A majority of patients (70%) self-identified as male gender and White (85%). One patient self-identified as gender fluid, and 10% identified as Hispanic ethnicity. Mean patient age was 16.1 years (SD 1.6) with participants ranging in age from 13 to 18 years. All participants had Fontan-palliated CHD per enrolment criteria for this pilot study.

Per parent/guardian report ($N = 19$ completed parent surveys), 53% of participating patients had at least one current or historic mental health diagnosis with the majority of these being ADHD (70%) or anxiety (30%). Nine patients had participated in therapy in the past, and 5 (26%) were currently receiving therapy/counseling services, while 3 (16%) were currently taking medications related to mental health, mood, or behaviour.

Feasibility and acceptability

WE BEAT group-based programme feasibility and acceptability are detailed in Table 2. Group cohorts ranged in size from 3 to 6 participants. A majority of patients achieved 100% session attendance (55%) with an additional 25% of patients participating in 75–80% of sessions. Of note, one cohort consisted of 4 total sessions instead of 5 due to technical difficulties (a disabled/wrong link) encountered at planned first session. In this instance, the contents for Sessions 1 and 2 were delivered in a single session. There were no other technical difficulties encountered throughout the pilot study experience.

Patients rated the programme very favourably, with a median programme rating of 9/10 (10 = great). Many patients rated the overall programme a 10/10 (47%) while none rated the programme below a 5/10. Individual sessions were also rated positively with median session rating scores ranging from 8.0 to 9.5 out of 10. Facets of the programme and design that were most appreciated by patients included the following: (a) “learning new coping skills” (74%), (b) “meeting others with heart disease” (47%), and (c) “fun activities” (42%). Overall, patients stated they were likely to recommend the programme to other young people with heart disease. Specifically, 53% were very likely (10/10) to recommend the programme to a peer while only 2 patients were not likely to recommend the programme with scores of 4/10 or below.

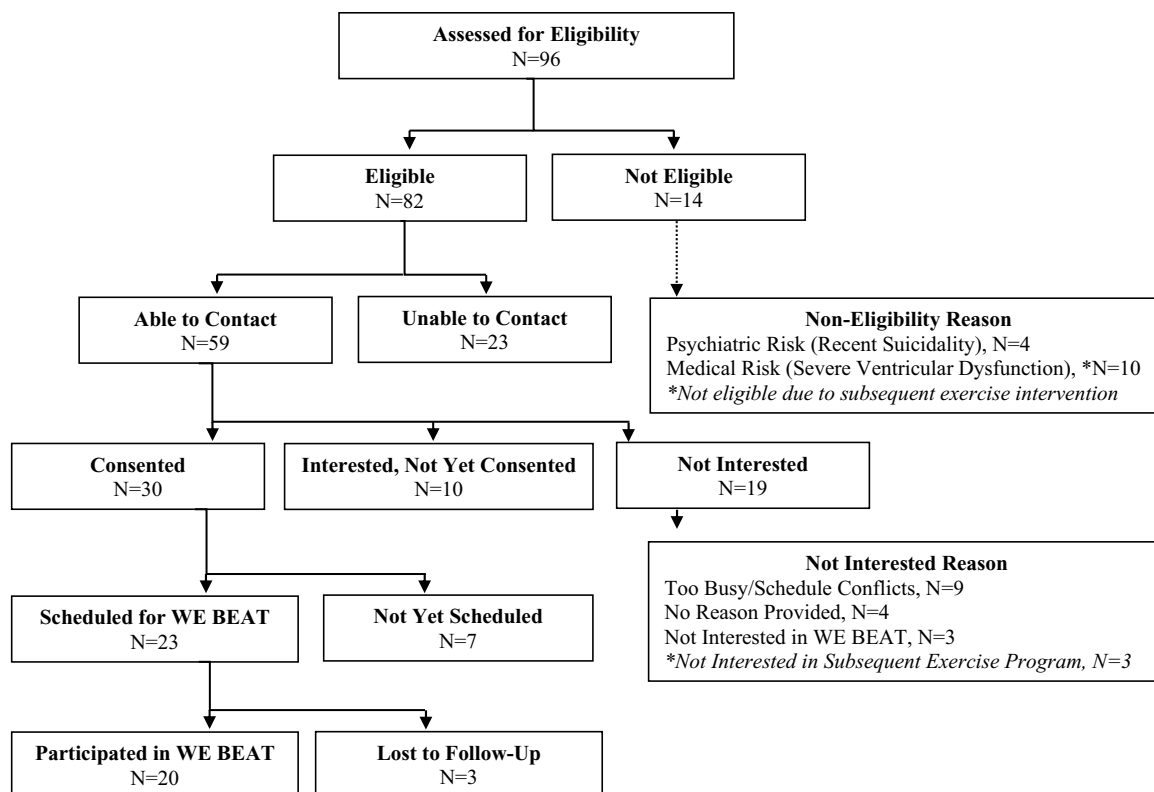


Figure 1. Participant recruitment and enrolment. CD-RISC = Connor–Davidson Resilience Scale.

Potential participants were most often identified via referral by primary cardiologist. Following patient recruitment and enrollment, time to administer and facilitate the programme ranged from 1 to 2 hours weekly during active cohort periods. Specifically, time breakdown included the following: (a) 15 minutes to send link/reminders to study cohort, (b) 40–45 minutes to conduct the WE BEAT session, and (c) additional time spent as needed contacting participating patients/families regarding follow-up surveys.

Preliminary effectiveness

Changes in scores from pre- to post-intervention are summarised in Figure 2a and b. Resilience scores, as measured by the Connor–Davidson Resilience Scale,^{20,21} increased from baseline to post-intervention as demonstrated by a medium effect size of $d = 0.44$. Depressive symptoms, as measured by the National Institutes of Health Patient-Reported Outcomes Measurement Information System Depressive Symptoms Scale, were reduced from baseline to post-intervention as demonstrated of a small–medium effect size of $d = 0.36$. Meaning and purpose in one’s life increased from baseline to post-intervention with a small effect size of $d = 0.26$. No meaningful effect sizes were observed for changes in anxiety symptoms, life satisfaction, positive affect, peer relationships, and benefit/burdens of illness over time.

Given our primary focus on resilience, item-level responses were explored. The overall proportion of the responses marked “True nearly all the time” for the Connor–Davidson Resilience Scale item,^{20,21} “Having to cope with stress can make me stronger”, was substantially increased pre- to post-intervention (from 6% to 53%). Pre-intervention, 29% of patients marked “True nearly all

the time” for the item “I can deal with whatever comes my way”. This was increased to 47% of respondents post-intervention.

Discussion

To our knowledge, WE BEAT is one of the first adolescent-directed telemedicine-based group interventions aimed at improving psychological well-being and resilient outcomes in young people with heart disease. Programme design, development,¹⁷ and pilot testing represent critical next steps in promoting psychological health and addressing mental health needs in a patient population with notable risk for adverse mental health sequelae.^{1–3} Our pilot results indicate that the WE BEAT group-based programme is both feasible and acceptable with preliminary findings demonstrating meaningful effects on increasing resiliency and decreasing depressive symptoms.

There is increased emphasis on prevention strategies as a means of mitigating the impacts of mental health concerns via the interactive teaching of new information or skills.²⁹ This focus on prevention, and particularly the acquisition of resiliency-focused skills to promote well-being, has only increased as COVID-19 drew additional attention to the inequities in access to care and exacerbated the already growing mental health crisis among youth.³⁰ However, continued barriers to accessing mental health care remain, including insurance barriers, geographical limitations to attending appointments, lengthy treatment waitlists, and lack of time given competing demands and other medical needs.^{4,31,32} Strategies to reduce barriers to accessing mental health care include group-based telemedicine interventions, such as WE BEAT and other digital health initiatives (e.g., mobile app intervention delivery), as well as utilising focused, brief interventions to reduce

Table 1. Patient demographics and family information (*N* = 20)

Patient gender	
Male	14 (70.0)
Female	5 (25.0)
Non-binary (self-described as gender fluid)	1 (5.0)
Patient age at baseline, years	16.1 ± 1.6
Patient race	
Asian	2 (10.0)
Multi-racial	1 (5.0)
White/Caucasian	17 (85.0)
Patient ethnicity: Hispanic	2 (10.0)
Family type	
Single-parent home	2 (10.0)
Married, both parents live at home	16 (80.0)
Mixed family home	1 (5.0)
Other	0 (0.0)
Not reported	1 (5.0)
Family's annual income	
< \$25,000	1 (5.0)
\$25,000 – \$50,000	1 (5.0)
\$50,000 – \$75,000	1 (5.0)
\$75,000 – \$100,000	6 (30.0)
> \$100,000	8 (40.0)
Not reported	3 (15.0)
Highest level of education completed by patient's mother	
Some high school	0 (0.0)
High school	1 (5.0)
Some college	9 (45.0)
Bachelor's degree	5 (25.0)
Professional degree (master's, doctorate degree)	4 (20.0)
Unknown/not reported	1 (5.0)
Highest level of education completed by patient's father	
Some high school	1 (5.0)
High school	3 (15.0)
Some college	2 (10.0)
Bachelor's degree	11 (55.0)
Professional degree (master's, doctorate degree)	2 (10.0)
Unknown/not reported	1 (5.0)
Parent's/guardian's relationship to patient	
Biological mother	16 (80.0)
Biological father	4 (20.0)
Parent/guardian race	
Asian	3 (15.0)
White/Caucasian	17 (85.0)
Parent/guardian ethnicity: Hispanic	2 (10.0)

*Data are presented as *n* (%) for categorical variables and mean ± standard deviation for continuous variable.

Table 2. Intervention feasibility and acceptability (*N* = 19 ~ 20)

Overall attendance, % (<i>N</i> = 20)	100 (75–100)
40	2/20 (10.0)
50	1/20 (5.0)
60	1/20 (5.0)
75	2/20 (10.0)
80	3/20 (15.0)
100	11/20 (55.0)
The overall WE BEAT programme rating (for all 5 sessions) (<i>N</i> = 19)	9 (8–10)
0 (very poor) to 4	0/19 (0.0)
5	3/19 (15.8)
6 or 7	0/19 (0.0)
8	3/19 (15.8)
9	4/19 (21.1)
10 (really great)	9/19 (47.4)
What did you like about the WE BEAT programme? (<i>N</i> = 19)	
Meeting others with heart disease	9/19 (47.4)
Learning new coping skills	14/19 (73.7)
Being able to participate by video/phone	5/19 (26.3)
Fun activities	8/19 (42.1)
Others	0/19 (0.0)
How likely are you to recommend the WE BEAT programme to other youth with heart disease? (<i>N</i> = 19)	10 (8–10)
0 (not at all)	0/19 (0.0)
1	0/19 (0.0)
2	1/19 (5.3)
3	0/19 (0.0)
4	1/19 (5.3)
5	0/19 (0.0)
6	1/19 (5.3)
7	1/19 (5.3)
8	3/19 (15.8)
9	1/19 (5.3)
10 (very likely)	10/19 (52.6)
Not reported	1/19 (5.3)

*Data are presented as *n* (%) for categorical variables and median (interquartile range) for continuous variables.

time demands and address lengthy waitlists. Findings from the current study demonstrating high feasibility and acceptability of this telemedicine-based group intervention are consistent with other youth digital health intervention literature.³³ The promising intervention effects on key outcomes via WE BEAT are consistent with prior literature reporting brief interventions as effective and accessible for youth with mental health concerns.^{34,35}

Participants in this pilot study exhibited improved resiliency, decreased depressive symptoms, and increased meaning and purpose in life. Prior resiliency intervention pilot studies for adults

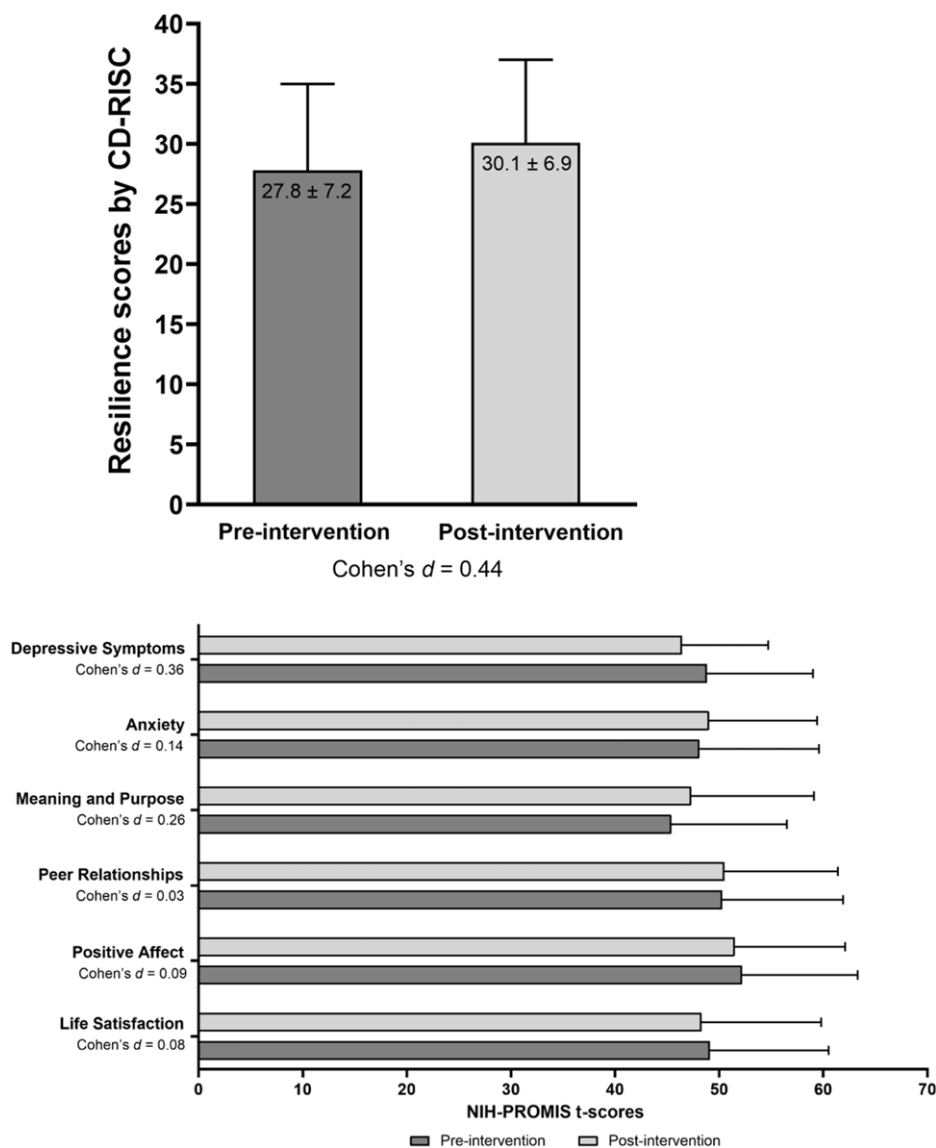


Figure 2. Intervention effects on resiliency and psychological health. NIH = National Institutes of Health; PROMIS = Patient-Reported Outcomes Measurement Information System.

with CHD have shown broadly comparable effects sizes for depression¹¹ and resiliency.¹⁰ Our findings add to the growing body of work showing that resilience in the setting of chronic and serious illness may be a malleable process and responsive to targeted intervention, even among paediatric samples.^{13,36} Of note, results from the WE BEAT pilot study showed no significant improvements in anxiety, life satisfaction, positive affect, peer relationships, and benefit/burdens of illness, mirroring the null findings of other brief resiliency interventions for adolescents/young adults with chronic illness, which had no intervention effects on anxiety^{11,13} or overall life satisfaction.¹³ It may be that these outcomes require more intensive intervention or that additional time is needed to “practice” and implement skills to decrease anxiety.

It is important to recognise the limitations of this pilot study to best inform interpretation of findings and future directions. First, while enrollment and acceptability for the WE BEAT group intervention were encouraging, we acknowledge that participation was part of a larger programme that included a subsequent exercise intervention. As such, patients interested and agreeable to participate in both a well-being and resilience education

programme and in a 6-month exercise programme may not be representative of the population at large. Some patients did not enroll in the study due to a lack of interest/fit with either arm of the larger programme. It is possible that enrolment would have been different if study participation was not inclusive of both WE BEAT and the exercise programme. Second, patients largely identified as White race (85%). While this is consistent with the racial demographics of the Fontan patient population at the study centre, this single-centre pilot sample limits our understanding of the acceptability, feasibility, and effectiveness of the WE BEAT programme across greater sociodemographic and regional diversity. Third, as is true of many multi-component interventions, the pilot design did not allow for in-depth study of potential mechanisms for change. It is possible that some components of the programme (e.g., peer community, coping skills instruction, interaction with psychology lead) were primary drivers of change while others were not. Lastly, while the pilot sample size was small by design, the study was limited in power to detect clinically significant intervention effects.

With these study limitations in mind, there are a number of important future directions for the WE BEAT programme. First,

multi-centre study with a larger, more diverse patient sample is a necessary next step for determining effectiveness. A more diverse patient sample can be accomplished through national/international recruitment as well as broadened diagnostic considerations. Further, continued community/patient co-design will be critical to ensuring that the WE BEAT programme and associated research aims are aligned with patient and family values, priorities, and needs. This emphasis on community-based participatory research will help to amplify programmatic reach and, hopefully, improved research representation across communities of colour and socio-economic strata.³⁷ Adaptations to increase reach are another important future direction. This includes possible adaptations for both younger (8 years and up) and older (18+ years) patient groups, as well as adaptations for non-English speakers.

Second, due to the critical need to rapidly deploy well-being and mental health-focused interventions for children and adolescents, and more specifically, for young people with heart disease,^{1–3} intervention implementation methods should be concurrently investigated. Implementation science decreases time to translation in clinical practice by simultaneously studying implementation methods at various levels (i.e., hospital/centre, clinic, patient).^{38–40} Implementation research questions may include intervention uptake based on centre differences (e.g., embedded mental health care clinician, large volume heart centre) and intervention delivery (e.g., group programme, app-based programme).

A final future direction is the study of WE BEAT intervention effects on cardiac and physical health outcomes given demonstrated associations between resiliency and adult cardiovascular outcomes.^{41–44} The growing literature across adult and paediatric chronic illness populations connecting resiliency with physical health outcomes underscores exciting future potential for the WE BEAT programme given these initial pilot results highlight WE BEAT programme feasibility, acceptability, and preliminary effectiveness at improving psychological well-being in young people with heart disease.

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Competing interests. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (Common Rule) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees (University of Michigan Medical School IRB).

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