Cardiology in the Young

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Developing the WE BEAT Well-Being Education Programme to foster resilience and build connection in paediatric heart disease

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Original Article

Cite this article: Cousino MK, Dusing CR, Rea KE, Glenn T, Armstrong B, Les AS, Hansen JE, Pasquali SK, and Schumacher KR (2024) Developing the WE BEAT Well-Being Education Programme to foster resilience and build connection in paediatric heart disease. *Cardiology in the Young* **34**: 1701–1707. doi: 10.1017/S1047951124000556

Received: 20 December 2023
Revised: 11 March 2024
Accepted: 17 March 2024
First published online: 16 April 2024

Keywords:
resilience; well-being; mental health; intervention; CHD

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Abstract

Background: The study of psychological well-being and related resilient outcomes is of increasing focus in cardiovascular research. Despite the critical importance of psychological well-being and related resilient outcomes in promoting optimal cardiac health, there have been very few psychological interventions directed towards children with heart disease. This paper describes the development and theoretical framework of the WE BEAT Wellbeing Education Program, a group-based psychoeducation and coping skills training intervention designed to improve psychological well-being and resilience in adolescents with paediatric heart disease. *Methods:* Program development was informed by patient and family needs and input gathered via large, international survey methods as well as qualitative investigation, a theoretical framework, and related resilience intervention research. *Results:* An overview of the WE BEAT intervention components and structure of the programme is provided. *Conclusions:* The WE BEAT Wellbeing Education Program was developed as one of the first resiliency-focused interventions in paediatric heart disease with an overall objective to foster positive psychological well-being and resilient outcomes through a health promotion and prevention lens in an accessible format while providing access to safe, peer-to-peer community building. Feasibility pilot results are forthcoming. Future directions include mobile app-based delivery and larger-scale efficacy and implementation trials.

Psychological well-being has been of increasing focus in the prevention of cardiovascular disease over recent decades.[1–3] Psychological well-being is not only the absence of negative psychological factors, such as anxiety or depression, but also the presence of positive psychological indicators, such as optimism and sense of purpose, which together increase healthy behaviours and improve cardiovascular function.[1,2,4] Resiliency is a related facet of psychological well-being and is defined as the process by which an individual harnesses internal, external, and learned resources to maintain well-being amidst a stressor,[5] such as chronic or critical illness.

Resiliency is a construct of growing importance in cardiovascular clinical care and research. In a large sample of nearly 1,000 adults with heart disease, multisystem resiliency, defined in the study as encompassing emotion regulation skills, social connectedness, and positive health behaviours, was associated with longer telomere length,[6] a biomarker of cellular ageing[7] that has been shown to be associated with improved cardiovascular outcomes.[8–10] Resiliency has been shown to be correlated with important outcomes in paediatric chronic illness populations as well, including improved health-related quality of life and decreased psychological distress in paediatric cancer patients,[11] better glycaemic control in adolescents with diabetes,[12] decreased depressive symptoms in youth with CHD[13] and better transition readiness in a paediatric chronic illness group.[14] In a recent study of over 300 individuals with CHD, higher resilience was correlated with fewer hospital admissions, lack of mental health diagnosis, increased exercise, and participation in peer support groups or disease-specific camps.[15] Causal pathways between resilience and health outcomes in paediatric heart disease are not well understood, and bi-directional relationships are very possible; however, interventions targeting resilience across other paediatric chronic medical conditions[11,16,17] and adult CHD groups have shown promise.[18,19] These interventions have also underscored potential areas for adaption and improvement to meet the specific needs of paediatric heart disease populations. Taken together, the literature suggests that resiliency is associated with important psychological and physical health-related outcomes and is a modifiable intervention target.

Despite the critical importance of psychological well-being and related resilient outcomes in promoting optimal cardiac health, there have been very few psychological interventions directed towards children with heart disease.[20] In a recent systematic review, only four adolescent-directed psychological interventions in young people with CHD were identified, and the efficacy of these interventions was inconsistent.[21] As such, the development, implementation, and testing of psychological interventions in paediatric heart disease has been identified as high priority by various organisations and stakeholders,[20,22,23] including patient and parent advocacy groups.[24] This paper describes the development and theoretical framework of the WE BEAT Wellbeing Education Program, a group-based psychoeducation and coping skills training intervention designed to improve psychological well-being and resilient outcomes in individuals with paediatric heart disease. Program development was informed by patient and family needs and input, a theoretical framework, and intervention research. An overview of the WE BEAT intervention components and structure of the programme is provided and future directions are detailed.

Methods

A series of patient-focused research studies led by our team over recent years, in addition to a theoretical guiding framework and relevant intervention research-informed WE BEAT intervention design.

Patient-informed intervention components

Previously, published patient-focused research by our team and others helped to inform WE BEAT intervention design. Specifically, a large, international psychosocial need assessment, a single-centre needs assessment, and a qualitative-mixed methods study informed overall need and patient-driven components of the intervention. In a previously published international survey of 1,200 patients with CHD and their caregivers across 25 countries (patient median age = 10 years, IQR = 4-28 years; 48% single-ventricle CHD), we sought to characterise the psychosocial support needs of children, adolescents and young adults with heart disease. Among respondents, 1 in 3 stated additional psychoeducation specific to promoting their own mental health/coping would be helpful.[25] Although this study was conducted during the COVID-19 pandemic, findings are similar to that reported in adult CHD, where 1/3 of patients stated interest in stress management and/or coping with heart disease interventions.[26] In a more recent survey-based single-centre needs assessment of 19 adolescents (13–18 years old) with single-ventricle CHD, 84% believed access to cardiology-specific counselling services would be helpful. Approximately a quarter of our large international sample desired increased access to peer support/connection opportunities,[25] while 63% of adolescents who provided input through our single-centre need assessment stated that having peer support for the issues they face with CHD would be helpful, consistent with others' findings regarding the importance of peer support.[26–28]

Lastly, our team recently completed a federally funded semi-structured interview study conducted with young people of diverse backgrounds ages 12–24 years with advanced heart disease and their caregivers. This larger study included aims beyond WE BEAT intervention development, including communication and medical decision-making needs in advanced heart disease, however, also included questions specific to resilience and psychosocial needs which subsequently helped to inform WE BEAT intervention development. Patients most commonly defined resiliency as one's ability to "bounce back" and/or to "keep fighting." When asked what helps young people with heart disease build resilience, a majority spoke to the importance of maintaining optimism and positivity, as well as social support, which is consistent with qualitative findings in adult CHD.[29] Similarly, when asked to give advice to peers with similar heart conditions, key themes centred around self-identity beyond one's heart disease (e.g., "don't let heart disease define you"), maintaining optimism and positivity (e.g., "it gets easier"; *Glenn et al., manuscript under review).*

Through the large-scale international survey research, single-centre needs assessment, and qualitative interview study, we ascertained that a meaningful subset of adolescent and young adult patients with heart disease 1) desire psychoeducation specific to coping with heart disease and 2) find value in peer-based social support. As such, the WE BEAT intervention was designed with emphasis on teaching coping skills through group-based peer-supported delivery.

Theory-informed intervention components

Although there are many definitions of resilience,[30,31] the one used by our team focuses on fostering and developing several promotive and protective factors and processes as opposed to a specific outcome.[5,32] Process-focused definitions emphasise that resilience is derived from multiple resources, both internal and external, and that one's resiliency is dynamic and changing.[33] It is not simply a trait, although innate characteristics and neurobiological factors can influence one's capacity to harness their resources and adapt.[33]

As such, resiliency is best understood through a multifaceted lens with biological, psychological, social, and ecological influences interacting across these systems.[34] The relationship between a stressor and the experience of resilient outcomes, such as reduced mental health symptoms, can be impacted by one's abilities to harness these resiliency resources across these interacting systems. Interventions aimed at increasing access to resiliency resources are one way of further promoting resilient outcomes in the face of adversity (Fig 1).

Many have identified various internal and external promotive and protective factors and processes important to resilience and positive development. Our WE BEAT intervention theoretical framework (Fig 1) is largely informed by the work of Masten[31,35–37] and Ungar et al.[34,38] Masten's well-known "shortlist" of promotive and protective factors and processes[36,39] includes: attachment, self-regulation, meaning-making, agency and mastery, intelligence and problem-solving, and self- and collective efficacy. Ungar and colleagues underscore relationships, control and efficacy, social justice, access to basic resources, identity and sense of cohesion as important resilience resources.[34] Informed by these various potential sources of resiliency, multisystemic resilience emphasises a "network" of available promotive and protective factors and processes when coping under stress.[38]

Core promotive and protective factors fostered in WE BEAT include self-regulation, identity, sense of cohesion, self-efficacy, and meaning-making, as well as collective efficacy and relationships, reflecting a mixture of both internal and external psychological and social resources. The group format is purposeful to further target social-level resilience resources. Lastly, accessibility and scalability have been considered critical to design from the outset, including intervention delivery via telemedicine and free participation, recognising that socio-economic, environmental,

https://doi.org/10.1017/S1047951124000556 Published online by Cambridge University Press

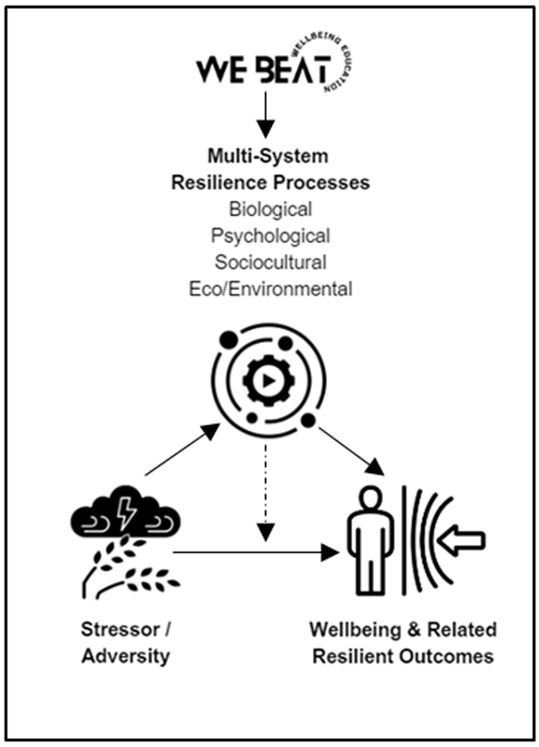

Figure 1. WE BEAT well-being education programme theoretical framework.

and cultural factors influence access to internal and external resilience resources (i.e., eco-environmental processes). As Ungar and Theron wrote, "Resilience is not solely a quality within individuals; it grows from access to and use of the resources needed to support mental health and well-being."[34]

Research-informed intervention components

In addition to patient and parent/caregiver-stakeholder engagement through formal qualitative research and patient/family advisory council input, programme design was informed by extensive review of the resilience intervention research, with particular focus on interventions within paediatric chronic illness and CHD. The Promoting Resilience in Stress Management intervention, originally piloted within the context of paediatric and young adult cancer and diabetes,[16] focuses on teaching four skills: stress management, goal setting, cognitive restructuring, and benefit finding. This brief intervention is delivered via four 30–60 minute individual sessions.[16] Using a randomised controlled trial design in paediatric and young adult cancer, Promoting Resilience in Stress Management participation was shown to be associated with improved resilience and disease-specific quality of life, increased benefit finding and hope, and reduced psychological distress.[11,40] In the initial pilot sample of inpatients and outpatients with cancer or diabetes, enrolment rates were 68% and 58% respectively with 80% of enrolled participants completing all sessions.[16] In the larger cancer-specific randomised controlled trial, 77% of eligible patients enrolled in the intervention study and 90% of participants received all intervention sessions.[11] Notably, in the larger randomised controlled trial, all sessions were delivered in-person within the context of a hospital admission or pre/post-oncology clinic visit.

The ACHD-CARE pilot randomised controlled trial was designed to improve resilience and quality of life in adults with CHD. This 8-session in-person group intervention was delivered to 42 participants. Core intervention components included relaxation, cognitive behavioural, and social skills training. ACHD-CARE was found to be acceptable and valued by participants with a medium effect size for decreasing depressive symptoms. Of note, only half of the participants attended all 8 study sessions, yet 71% attended at least 4 sessions. It was reported that enrollment (~ 32% enrollment rate) was impacted by barriers to in-person attendance, including transportation and time.[18]

The Stress Management and Resiliency Training Program-Relaxation Response Resiliency Program (SMART-3RP) was recently piloted in a sample of 12 adults with CHD.[19] This 8-week telemedicine-based, psychologist-led, group programme focused on mind-body, cognitive behavioural, and positive psychology skills. Among those who enrolled in the study (45% enrolment rate), group session attendance was excellent (≥80%). Results demonstrated intervention feasibility and a medium effect size for improvements in health-related anxiety and resiliency 3-month post-intervention. Participants noted that shorter sessions (i.e., 60 minutes compared to 90 minutes) would be welcomed, as well as more heart disease-specific content.[19]

These successful intervention research programmes further informed our design. Specifically, similar to Promoting Resilience in Stress Management,[11,16] we aimed to develop a brief intervention, but sought to incorporate a social community component through a group-based offering much like ACHD-CARE[18] and SMART-3RP[19] given the importance of peer support identified by our patients and through larger-scale research with the paediatric heart disease population.[15,25] Moreover, similarly to SMART-3RP, we sought to make the programme as accessible as possible via telemedicine delivery.[19]

Results

WE BEAT intervention delivery

The WE BEAT programme was initially designed for delivery via telemedicine-based group format. Adolescent-aged group cohorts consist of approximately 4–10 similarly aged peers with analogous cardiac diagnoses. Groups are conducted via HIPAA-compliant video conferencing technology and facilitated by a licenced psychologist or psychology trainee working under the direct supervision of a licenced psychologist. The intervention programme includes five weekly 45-minute sessions. The five modules are detailed below. Each session follows the same outline: (I) Welcome/Check-In, (II) Evidence, (III) Skill-Building, (IV) Goal Setting. During the *Welcome/Check-In*, participants are invited to share via audio or text skills they tried or practised during the week prior (5 minutes). Research evidence specific to the module theme (5–10 minutes) is then described in a developmentally appropriate way. The *Evidence* is shared via teen-friendly graphics and media, building "buy-in" for skill development. Participants then learn three evidence-based *Skill-Building* activities specific to the module. In session practice of each skill is facilitated (15 minutes). The group session ends with each participant sharing via audio or text what they liked/disliked and engaging in *Goal Setting* regarding skill practice.

Mixed media is utilised throughout the programme (e.g., videos, audio, polls). Content is specific to the chronic illness and/or heart disease journey. For example, evidence is reviewed regarding mindfulness practice and health impact. A heart journey gratitude story is shared by a paediatric cardiologist with CHD

https://doi.org/10.1017/S1047951124000556 Published online by Cambridge University Press

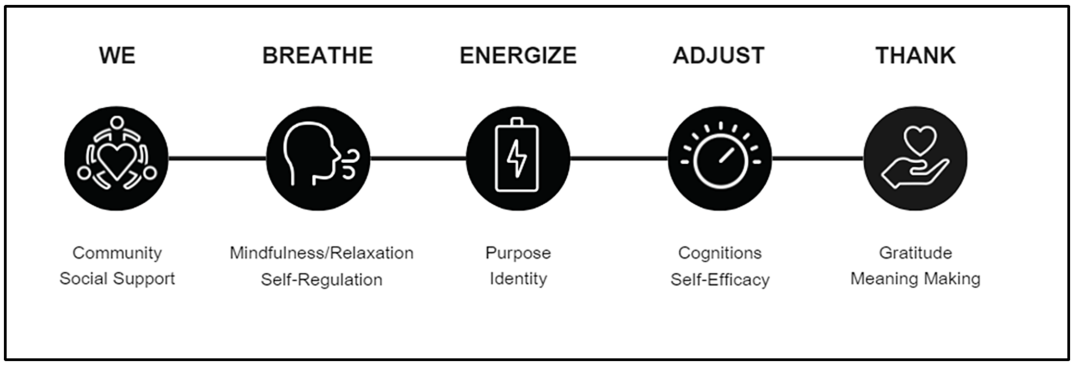

Figure 2. Overview of WE BEAT programme modules.

themselves. An accompanying WE BEAT workbook is also provided to participants ahead of the first session. It is recommended that participants use the workbook to set goals, track practice, and keep notes related to sessions as helpful.

WE BEAT intervention modules

Building upon patient-focused research, resilience theory and successful intervention design, the five WE BEAT modules include the following: (1) **W**ellbeing **E**ducation, Introduction and Community Building, (2) **B**reathe, Mindfulness and Relaxation-Based Skills, (3) **E**nergise, Positive Psychology Skills, (4) **A**djust, Cognitive Skills Training, and (5) **T**hank, Gratitude Practice (Fig 2).

Wellbeing Education (Module 1). Peer support has been shown to correlate with higher quality of life[41] and resilience.[15] While peer support is regularly noted as important to the CHD experience, there is research across other paediatric chronic illness groups to suggest that adolescents do not find disease-specific online forums/pages to be relevant.[42] Those who engage in more formalised disease-specific mentoring report high satisfaction.[43] As such, the WE BEAT programme is centralised on group-based well-being education to provide disease-specific peer connection, while also socialising resilience skill-building and processes. Module 1 activities include baseline survey completion, group icebreaker/community building activity, and group sharing on meaning of resilience.

Breathe (Module 2). Mindfulness is a state of consciousness involving paying attention in the present moment, purposefully and in a non-judgmental way.[44,45] Relaxation strategies are one method of scaffolding towards and developing the skill of mindfulness. The mechanism of action through which mindfulness leads to improved well-being is thought to be through the shift in perspective or reperceiving that comes with attending in the moment with openness and a non-judgmental attitude. This perspective shift can subsequently contribute to further mechanisms for change, which include values clarification, improved self-regulation, and increased cognitive and emotional flexibility.[46] The benefits of mindfulness for children with physical medical conditions have been demonstrated through systematic review, specifically in decreasing depressive and anxiety symptoms.[47] Recent meta-analyses have indicated positive influences of mindfulness-based interventions among those with cardiovascular diseases across ages, including moderate to large effects in reducing anxiety, depression, stress, and blood pressure.[48] Specifically among adolescents with CHD, a mindfulness-based stress reduction group intervention was associated with decreased illness-related stress and anxiety and improvements in application of skills to real-life stressors.[49] Module 2 skill-building activities include instruction and practice in diaphragmatic breathing, a guided imagery experience, and a mindfulness exercise (i.e., word focus).

Energise (Module 3). Positive psychology principles centre on understanding and promoting the conditions, traits, and individual strengths to enhance well-being and life satisfaction while also buffering against future distress.[50] These principles include, but are not limited to, optimism, self-compassion, and life's purpose. Efforts to promote these and other positive psychology principles are thought to impact outcomes through mechanisms of both improved intrinsic well-being, such as decreasing depression, anxiety, and stress[51] as well as promotion of extrinsic well-being associated with social relationships, community building, and relationship with broader embedded systems, such as cultural, political, or economic systems.[50] Specific to cardiology and heart disease, the benefits of positive psychology in cardiovascular disease include both direct impacts on neurobiological process (e.g., reducing blood pressure) and indirect impacts on health behaviours and utilisation of psychological resources, such as likelihood of seeking social support, greater emotion regulation, and uptake of exercise recommendations.[1] Module 3 skill-building activities include reflections and group sharing on purpose and passions, as well as brainstorming specific to increasing daily movement.

Adjust (Module 4). Cognitive behavioural therapy centres on the core premise that dysfunctional thoughts lead to psychological disturbances, and modification of such thoughts can produce improvements in behaviours and emotions.[52,53] Through instruction in specific cognitive skills, such as cognitive restructuring, an individual is taught to identify, evaluate, and modify unhelpful or inaccurate cognitions, ultimately improving psychological well-being.[52] In recent years, therapeutic approaches within the cognitive behavioural tradition (e.g., Acceptance and Commitment Therapy, Dialectical Behavioural Therapy) have shifted to include a focus on acceptance-based strategies as well.[54] Among children with a chronic medical condition, cognitive behavioural therapy is an effective treatment for anxiety and depression.[55] Specific to youth with CHD, a psychosocial intervention incorporated strategies to build cognitive flexibility, including acceptance and cognitive reappraisal, resulted in improved resiliency among adolescents in South Korea.[56] Module 4 skill-building activities include introductory instruction in thought challenging, self-talk, and radical acceptance.

Thank (Module 5). While gratitude can be conceptualised in different ways, dispositional gratitude refers to the "generalised tendency to respond with grateful emotion, by noticing and

https://doi.org/10.1017/S1047951124000556 Published online by Cambridge University Press

appreciating one's positive experiences and achievements."[57] In a recent meta-analysis, dispositional gratitude was found to be moderately positively correlated with aspects of positive well-being, including happiness, life satisfaction, and positive affect.[57] The impact of gratitude on well-being is thought to occur via multiple mechanisms, including positive interpretive biases when appraising benefit,[58] improved coping,[59] and building positive resources for use in future times of stress.[59,60] A recent systematic review found that gratitude-focused interventions are potentially promising for improving several physical health conditions, including subjective sleep quality and glycaemic control.[61] while another review concluded that gratitude interventions may improve some aspects of cardiovascular health and markers of inflammation.[62] Additionally, gratitude may improve health behaviours important to the development and progression of cardiovascular disease, including physical exercise, diet, and medication adherence.[63,64] Module 5 activities focus on the practices of self-gratitude, others gratitude and heart-related gratitude

Discussion

The WE BEAT Wellbeing Education Program was developed as one of the first resiliency-focused interventions in paediatric heart disease with an overall objective to foster positive psychological well-being through a health promotion and prevention lens in an accessible, digital health format while providing access to safe, peer-to-peer community building. A single-centre feasibility pilot trial of the WE BEAT Wellbeing Education Program in telemedicine group format is currently underway in a sample of 13–18-year-olds with Fontan-palliated CHD. Acceptability results are very encouraging thus far and pilot study results are forthcoming. In addition to pilot research, we envision future directions of this intervention programme to include digital health delivery options, larger-scale implementation, effectiveness and mechanistic trials, and age-based and multi-language adaptations.

There has been an increasing call for digital mental health interventions developed via human-centred design to increase accessibility and reduce disparities in care.[65] Adolescent use of smartphones is nearly ubiquitous in the United States, with average age of mobile phone acquirement around 11–12 years of age, even among youth from lower-income households.[66] Recent 2022 national survey data from the Pew Research Center approximate 95% of U.S. teens have access to a smartphone and 97% of U.S. teens report using the Internet daily (www.pewresearch.org). As such, a WE BEAT responsive website was developed as a first step in expanding this intervention programme beyond the telemedicine group format. Initial user co-design, input, and testing of the responsive website with diverse stakeholders is nearly complete. Technical specification design for a WE BEAT app based upon data gathered from the website feedback is underway. Ultimately, the goal of the app would be to reach more patients and families in need, while also aiding in the group-based intervention delivery or allowing users to independently complete the programme in a self-directed way via the app.

In addition to larger-scale effectiveness and implementation trial research, future mechanistic studies will be needed to better understand change agents within this multicomponent, multisystemic intervention. This will require large samples of participants followed longitudinally and the use of advanced statistical modelling. Further, the impact of WE BEAT programme participation on biomarkers and health outcomes is an exciting future phase of this work. Building upon the multisystem resiliency framework, this would enable investigation of biological processes also at play, as well as the improved understanding of correlational and causal pathways between resilience and health outcomes.

Continued co-design with patient and family stakeholders will remain a cornerstone of this programme as adaptations are made across diverse age, disease and cultural/language groups. We firmly believe that interventions of this nature are only successful if able to reach across socio-economic and racial/ethnic strata, especially given demonstrated disparities in mental health diagnosis and treatment among Black and Hispanic youth with CHD.[67,68] As such, community-based participatory research practices will be foundational to propelling future iterations of this intervention forward.[69]

It is important to acknowledge barriers encountered, lessons learned and limitations inherent to this intervention design. Intervention design is often done through a clearly defined and delineated programme of research. The ORBIT model, which is regularly referenced by the NIH for the design and optimisation of behavioural health interventions, is one such example.[70] While our approach builds upon some guiding principles of this model, we acknowledge that this intervention was spurred first and foremost by clinical need. The guiding research, while related to resilience, was not solely focused on this intervention design. While these could be appreciated as limitations, we also have learned lessons in the importance of flexibility, responsiveness to patient/family needs, and real-world responsiveness and applicability when developing patient-focused interventions. It has been estimated that it takes 17 years for research to reach patients in clinical settings.[71] This is simply too long to wait to address the psychosocial needs of young people living with heart disease. Additionally, for some young people, the group format and telemedicine-based delivery may not be ideal. Scheduling challenges will likely be additional limitations. Further, funding to sustain WE BEAT will likely depend on in-kind support and continued advocacy as current insurance reimbursement standards do not regularly cover preventative, psychoeducation-based mental health care such as this, particularly in the absence of a mental health diagnosis. Despite these limitations, the WE BEAT Wellbeing Education Program begins to address the considerable need for psychosocial health-focused interventions in paediatric heart disease through a positive psychological well-being lens as informed by patients, theory, and past research. This initial programme design manuscript sets the stage for forthcoming pilot studies, larger multi-site trials and future adaptations.

Acknowledgements. None.

Financial support. This work was supported by funding from the National Heart, Lung, and Blood Institute (M.C., K23HL145096) as well as philanthropic support provided to the University of Michigan Congenital Heart Center.

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, United States of America) and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the institutional committees (University of Michigan).

https://doi.org/10.1017/S1047951124000556 Published online by Cambridge University Press

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