



From worries to resilience: a qualitative study of the psychosocial experiences of diverse adolescents and young adults with heart failure and their caregivers

Original Article

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Abstract

Background and Objectives: Despite advances in treatment and outcomes for paediatric heart failure, both physical and psychosocial comorbidities remain notable among this patient population. We aimed to qualitatively describe the psychosocial experiences of adolescent and young adults with heart failure and their caregivers' perceptions, with specific focus on personal challenges, worries, coping skills, and resilience. **Methods:** Structured, in-depth interviews were performed with 16 adolescent and young adults with heart failure and 14 of their caregivers. Interviews were recorded and transcribed. Content analysis was performed, and themes were generated. Transcripts were coded by independent reviewers. **Results:** Ten (63%) adolescent and young adults with heart failure identified as male and six (37.5%) patients self-identified with a racial or ethnic minority group. Adolescent and young adults with heart failure generally perceived their overall illness experience more positively and less burdensome than their caregivers. Some adolescent and young adults noted specific worries related to surgeries, admissions, major complications, death, and prognostic/treatment uncertainty, while caregivers perceived their adolescent and young adult's greatest worries to be around major complications and death. Adolescent and young adults and their caregivers were able to define and reflect on adolescent and young adult experiences of resilience, with many adolescent and young adults expressing a sense of optimism and gratitude as it relates to their medical journey. **Conclusions:** This study is the first of its kind to qualitatively describe the psychosocial experiences of a racially and socioeconomically diverse sample of adolescent and young adults with heart failure, as well as their caregivers' perceptions of patient experiences. Findings underscore the importance of identifying distress and fostering resilient processes and outcomes in young people with advanced heart disease.

Introduction

Paediatric heart failure is a complex and burdensome condition that carries an incidence of 0.9–7.4 per 100,000 children.^{1,2} For children with CHD admitted to the hospital with severe heart failure, in-hospital mortality reaches 26%. For those awaiting heart transplantation, 22% will die before an organ becomes available.² Despite the increased use of advanced therapies and ventricular assist devices, there remains a high burden of morbidity and mortality among this population,² as well as impaired quality of life.³ Understanding modifiable risk and resilience factors is critically important to improving physical and psychosocial outcomes in paediatric heart failure.

Psychological health and well-being is one such modifiable factor. Both negative and positive psychological health have important implications for cardiovascular health and cardiac-related outcomes.^{4,5} In the general population, negative psychological health, such as anxiety and depression, has been associated with an increased risk of acquired cardiovascular disease.⁴ Research to date has largely focused on characterising risk of negative psychological health in paediatric heart disease. Among the general CHD population, significantly higher rates of depression, anxiety, post-traumatic stress, and medically related fear are seen in comparison to healthy counterparts.^{6–12} High rates of mental health diagnoses and significant patient and family psychosocial distress have been recognised in paediatric ventricular assist device and heart transplant populations.^{13,14}

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Beyond mental health morbidity, health-related worries and stressors are understandably notable for patients and families living with CHD. Several studies have catalogued the great amount of worry that parents of individuals with CHD have for their children. This worry is not limited to the time of diagnosis but often expands to the future health of their child and of the rest of the family.^{15–19} Similar findings are seen in those living with CHD. One study of young patients with CHD reported that 71% of individuals experienced anxiety, and 55% experienced worrisome thoughts, leading to a disruption in daily living.²⁰

It is important to recognise that while mental health morbidity and health-related worries are common, these risks and experiences are not ubiquitous. Many patients do not experience negative psychological health in the setting of their advanced heart disease. Promotive and protective factors for positive psychological health, however, have not been well studied in paediatric heart disease. Resilience, which has been defined as the process by which one harnesses internal, external, and learned resources to cope with adversity, is one facet of positive psychological health.^{21,22} Studies in patients with chronic illnesses and their caregivers have demonstrated that both patient and parental resilience is associated with better quality of life, greater social support, and lower distress.^{23–27} In a study of 332 individuals with CHD (17.2 ± 5.1 years), higher resilience was correlated with fewer hospital admissions, lack of a mental health diagnosis, increased exercise, and participation in peer support groups or disease-specific camps.²⁸ In paediatric patients living with other non-cardiac chronic illnesses, resilient individuals were more likely to have higher transition readiness and better disease control.^{29–31}

While one's resilience processes and resources are likely to have important implications for both psychological and physical health in young people with heart disease, the concept is largely understudied within this patient population. This federally funded single-center study aimed to qualitatively describe how adolescents and young adults with heart failure view their own personal challenges, worries, coping skills, and resilience. Parental perspectives on their child's coping and resilience were also obtained. Due to the qualitative nature of this study, there were no *a priori* hypotheses. The overall objective of this qualitative investigation was to inform the design of patient-centered interventions focused on well-being, resilience, and positive psychological health paediatric advanced heart disease, as no psychological interventions have been developed or piloted in the growing paediatric heart failure population.

Methods

Study design and population

This qualitative methods study utilising semi-structured interviews was approved by the local Institutional Review Board. Single site recruitment was completed at a U.S.-based Midwest children's hospital. Patients (12–24 years) with heart failure symptoms meeting criteria for NYHA Classes II–IV heart failure were eligible (i.e., limitations in physical activity, fatigue, palpitations, dyspnoea). Parents of patient participants meeting this inclusion criteria were also eligible. Adolescent and young adult patient and parent participants were excluded if (a) they had experienced suicidal intent or symptoms of psychosis in the past 6 months, (b) had moderate cognitive impairment or developmental disability (e.g., IQ below 55 per self, parent, or provider report), or (c) were not English-speaking. In addition, adolescent and young adult

participants who (d) were intubated, unable to respond verbally, or with active delirium as diagnosed by a physician were excluded.

Eligible patients were identified and approached following a thorough review of our institutions heart failure and transplant outpatient clinic and inpatient cardiology census by the research team. After identification, we obtained approval from the patient's primary cardiology care team before approaching the individual. For those patients who were interested, enrollment occurred in both the inpatient and outpatient setting. Patients of research team members were eligible for study participation; however, study enrollment procedures and the interview were conducted by a study team member who was not active in the care of these patients.

Purposive sampling³² was utilised to recruit approximately: (1) 8 adolescent patients ages 12–16 years of age, (2) 8 adolescent/young adult patients ages 17–24 years of age, and (3) 14 parents of adolescent/young adult patients enrolled in study as well as to ensure diverse representation in the study sample. Adolescent and young adult-only or parent-only participation was permitted. A total sample size of 30 was targeted for achieving theme saturation.³³ The COREQ (CONsolidated criteria for Reporting Qualitative research) Checklist was used for describing methods and reporting results (Supplementary File).

Methods and measures

Written assent/consent was obtained from all participants and legal guardians prior to interview initiation. Semi-structured interviews were conducted by a nurse research coordinator across a variety of settings depending on patient location (i.e., inpatient cardiology room, cardiology clinic consult room, HIPAA-compliant telemedicine). Participants were reminded of the general overall purpose of the study as well as the interviewer's role (i.e., nurse research coordinator) at the start of the interview. All interviews were audio recorded and transcribed for analysis purposes. Duration of interviews ranged from approximately ~30–60 minutes. The semi-structured question guide was developed by the study team as informed by the literature and a related survey-based study in adolescents and young adults with heart failure³⁴ with additional review from experts representing psychology, cardiology, palliative medicine, developmental/behavioral paediatrics, adolescent medicine, and bioethics. The drafted question guide was also reviewed by patient/family volunteers with feedback obtained. Questions were developed to be short, open-ended, one-dimensional, and without medical jargon.³³ The adolescent and young adult interview included 12 question prompts, while the parent interview included 14 question prompts. Questions specific to this current analysis focused on (a) worries, (b) challenges, (c) sources of strength/support, (d) coping strategies, (e) defining resilience, and (f) fostering resilience. Caregiver interview analysis was focused on their perceptions of the patient's worries, coping, and resilience. Interview transcripts were stripped of personal identifying information to protect each participant's identity before content analysis. Each patient and caregiver participant received a \$50 gift card for compensation of their time completing study interview and the demographic/background survey.

Analysis

Descriptive statistics (i.e., frequencies and percentages) were performed to describe the sample. Content analysis was utilised to code interview data.³⁵ Three authors (TG, CS, MC) independently

read each of the interview transcripts to obtain a holistic view of the data. Themes were generated using the constant comparative method,³⁶ and supporting quotes were identified. A coding book was developed by the senior author and study PI (MC) within Microsoft Excel. All transcripts were coded by two independent coders (TG, CS). Discrepant coding was reviewed and discussed. Reliability coding was completed on 20% of transcripts to enhance validity by a third coder (MC).

Results

Participants

A total of 30 participants completed the study ($N = 16$ adolescent and young adult patients with heart failure and $N = 14$ caregivers). A total of 23 eligible patients were approached for the study with 16 consenting to study participating (70% enrollment rate). The most common reason for declining study participation was “not interested in participating in any research studies.” Among patients screened and deemed not eligible per pre-determined criteria, the most common reason for ineligibility was developmental delays impacting study participation (i.e., non-verbal). Consenting patient participants ranged in age from 13 to 22 years ($M = 17.06$; $SD = 3.26$), and 63% ($N = 10$) identified as male. Five patient participants identified as non-Hispanic Black, while one participant identified as Hispanic, multi-racial (37.5% self-identifying with racial or ethnic minority group). The majority of patient participants (62.5%) had heart failure in the setting of CHD, while the remaining participants ($N = 6$; 37.5%) had a primary cardiomyopathy diagnosis. Patient and caregiver demographics are shown in Tables 1 and 2.

Fourteen caregivers completed the study ($N = 9$ biological mothers, $N = 1$ stepmother, $N = 4$ biological fathers). Caregivers described their families as married/both parents at home ($N = 7$, 50%), mixed family home ($N = 4$, 29%), or single parent home ($N = 3$, 21%). A subset of caregivers (29%) reported a family income below the Federal Poverty Level (<\$25,000 in 2023), while one patient-only respondent reported the same, resulting in approximately 1/3 of the sample indicating living among impoverished living conditions. Among known parental education levels reported ($N = 26$), 5 parents had not completed high school (19%) and 9 parents held a Bachelor’s, Master’s, or Doctoral-level degree (35%).

Worries and challenges among adolescents and young adults with heart failure and their caregivers’ perception

Adolescents and young adults with heart failure reflected on worries and challenges that they face personally, while caregivers of adolescents and young adults shared their perceptions of worries and challenges their children face (Table 3). At times, given the semi-structured nature of the interview, parents went on to discuss their own worries and coping. Over half of the adolescents and young adults with heart failure (8/15, 53%) responded that living with heart disease causes little or no difficulties in their life. One participant responded, “I have nothing to compare it to, so it’s just normal for me.” In contrast, nearly all caregivers (12/14, 86%) responded that their child had a moderate or severe amount of difficulty in their life. When asked about specific worries that adolescents and young adults with heart failure experience, 30% of patients responded with having no specific worries. One participant responded, “I have no worries; when you’re sick you look at life differently.”

Table 1. Patient demographics

Characteristic	
Gender; N (%)	
Male	10 (63)
Age (Years); Mean (Range)	
	17.06 (13–22)
Ethnicity; N (%)	
Hispanic	1 (6)
Non-Hispanic	15 (94)
Race; N (%)	
Black 5	(31)
Multi-Racial	1 (6)
White	10 (63)
Etiology of Heart Failure; N (%)	
CHD	10 (62.5)
Cardiomyopathy	6 (37.5)

Table 2. Caregiver demographics

Characteristic	
Participating Caregiver Role; N = 14 (%)	
Biological mother	9 (64)
Stepmother	1 (7)
Biological father	4 (29)
Family Structure; N = 16 (%)	
Married/Both parents at home	9 (56)
Mixed family home	4 (25)
Single parent home	3 (19)
Parental Educational Level; N = 26 (%)	
Did not complete high school	5 (19)
High school diploma	5 (19)
Some college	7 (27)
Bachelor degree	7 (27)
Professional degree	2 (8)
Household Salary; N = 14 (%)	
< \$25,000	4 (29)
> \$25,000	10 (71)

Causes of worry

For adolescents and young adults who acknowledged having worries, nearly half responded that major surgeries, hospitalisations, and therapies (e.g., interventions) were their main cause of concern (6/14, 43%). In response to what their main worry is, one patient respondent noted, “Everything. I’m scared I’m going to get into like a really, really sick state or you know this is going to go on worse and worse and I’m really not going to be able to do anything because it’s hard for me to do a lot of stuff right now. All these medical procedures and stuff... the transplant just very, very much worries me.” Caregivers generally perceive their children

Table 3. Examples of illustrative quotes

Theme	Respondent	Illustrative quotes
Worries	AYA with HF	“When you are sick it’s kind of, it makes you look at life and death a totally different way, it’s not scary. I don’t really think I have any worries. Yeah, I don’t think I have any.” (3) “Nothing really worries me that much. I mean, there are good doctors out there that I have.” (10)
	Caregiver, regarding AYA with HF	“Dying, you know he/she/they, most kids at his/her/their age feeling invincible and he/she/they don’t have the privilege of feeling invincible.” (2) “I think to be honest, would be him/her/they passing away or getting sick” (7)
Challenges	AYA with HF	“Not being able to do everything that my friends can do” (1) “Really just day to day life, sometimes I can get up I’m perfectly fine and the next day I get up and I’m tired, I’m weak, I’m fatigued, I can’t do anything. I can’t . . . like I can’t have a teenager life . . .” (12)
	Caregiver, regarding AYA with HF	“His/her/their biggest challenge would be the mental part of not being, dealing with [crying] doing what his/her/their friends do. I can’t talk [crying]. It’s just that’s hard because he/she/they’re, hanging out with a bunch of kids and they’re getting bigger and stronger and he/she/they’re getting a little bit taller but he/she/they’re still a string bean.” (1) “Having a brother that can go out and do whatever he/she/they want while he/she/they stay behind” (12)
Support	AYA with HF	“I have a good support team, no matter if it’s at the hospital or if it’s my siblings or my mom, I have a very good support team, but mainly it’s the people at the hospital . . . the people I’ve had on my team since like two.” (3) “I have a lot of friends that are very supportive. My family is great, my parents have been there with me through my entire life . . . I do occasionally go to a psychologist.” (9)
	Caregiver, regarding AYA with HF	“Friends, family, and prayer . . . other families that we met early on that was especially helpful . . .” (2) “We have a lot of support from our family and he/she/they has really good doctors too, so that helps.” (4)
Coping	AYA with HF	“Music and puzzles, poetry, anything that allows me to express my emotions and I think puzzles are, it allows me to turn my brain off. So, it allows me to forget that I’m in the hospital or I’m sick or something like that.” (3) “I like to draw a lot. Sometimes I just write in a notebook like how I feel or like what I did that day just to keep me occupied . . . it’s the most random things but I find it so relaxing to just draw or whatever.” (7)
	Caregiver, regarding AYA with HF	“He/she/they has a journal that he/she/they write in. He/she/they has a stress ball.” (8) “He/she/they plays video games all day long. He/she/they go to work, come home, shower, change, and go to his friend’s house and they play video games all night long. He/she/they watches YouTube or Netflix or things like that too. He/she/they’ll read a little bit here and there. He/she/they likes immersing themselves in those other worlds, you know, that seems to be what it all is . . . submersing themselves into other worlds and maybe that’s what helps him/her/they.” (11)
Defining Resilience	AYA with HF	“Somebody who can bounce back from a lot of stuff, someone who’s been through a lot of stuff but also they know that it’s just another obstacle in the road.” (3) “Not letting things get to you, or being strong.” (6) “It means dealing with the adversity that life has thrown your way and making your life the best that it can possibly be with the circumstances of which you found yourself in.” (9)
	Caregiver of AYA	“The ability to put up with whatever comes along and just be yourself and kind of bounce back from whatever hits you in the process.” (2) “Sticking with it, keep coping just like we’re doing . . . don’t just give up and don’t just stop.” (6) “Never lay down . . . fight to the end.” (14)
Personal Example of AYA Resilience	AYA with HF	“The night I first got sick . . . this was not a 1–2 day thing, I was going to be dealing with this for a really long time . . . the old me passed away but a new me was born, a stronger me, because I don’t think the old me would have been able to deal with the stuff that I had to deal with.” (3) “Before this appointment with the [hospital], I was you know, worried that I was going to get listed for transplant and so I think that it took a lot of mental power to prepare myself for those conversations but at the same time tell myself obviously if it’s time, it’s time. I trust them.” (9)
	Caregiver, regarding AYA with HF	“He/she/they always does (shows resilience). I can’t think of a specific time because he/she/they does all the time.” (4) “I cannot pinpoint one because over 22 years, I could probably come up with 1000 (times he/she/they have been resilient).” (11)
AYA Advice to Others	AYA with HF	“It gets easier, it gets easier. After a while you kind of just, it becomes your normal routine. It’s a part of our life, it’s the life we were dealt and it was the cards we were dealt and we have to play the hand we were given. It’s going to take a long time, it’s going to be a long road but it gets easier, a lot easier.” (3) “It’s hard but it’s what it is, and you’ve got to make the best out of it you know, it’s not easy . . . don’t let anything stop you because you have a heart issue . . . don’t let anything stop you, like do what the other kids are doing.” (7) “Just stay the course. It’s a tough road but in the end I’m very normal.” (9) “You’ve just got to believe that everything’s going to get okay and then like that if you do that, you might have a great life if you don’t get yourself down about it.” (15)

worry most about major complications such as stroke, death, or life-limiting adverse events (6/17, 35%). In response to what worries their child with heart failure most, one caregiver stated, “[Name] has talked about his/her/their funeral, he/she/they have talked about what he/she/they wants done with his/her/their body and he/she/they wants me to grant all his/her/their wishes [crying] and that’s really hard for him/her/them.” No caregiver reported their child as having no worries, despite 30% of patients reporting no worries specific to their heart disease.

Challenges faced

When asked about the challenges that they face, adolescents and young adults with heart failure mostly indicated declining physical health and ability as their biggest challenge (7/17, 41%). “One step forward, three back(wards),” as one participant recalled. Another common theme among patients was “not being able to do everything that my friends can do.” Several reported that their ongoing health concerns and challenges negatively impacted their peer relationships and connections with others (4/17, 24%). This was a major challenge that caregivers also perceived in their child, with most responses citing their child’s inability to do things that their peers do as a notable challenge they face (8/22, 36%). One caregiver recalled, “his/her/their biggest challenge is trying to keep up with his/her/their friends who do not have heart issues. You know, they’re playing sports, they’re swimming, they’re doing this, they’re doing that and then he/she/they can’t do all that and he/she/they wants to be out there with them . . .”

Support and coping among adolescents and young adults with heart failure and their caregivers’ perception

Adolescents and young adults with heart failure and their caregivers answered open-ended questions about their support system and coping (Table 3).

Support systems

All participants, both patients and caregivers, were able to identify one or more sources of patient-specific support. There was a strong consensus among both patients (26/32, 81%) and caregivers (17/23, 74%) that family and friends provided the highest level of support to adolescents and young adults with heart failure. One patient spoke on their support, “My family is great, my parents have been there with me through my entire life, making sure my health was a priority was something that I’m super thankful for.” On support systems for their child, one caregiver responded, “Through us, he/she/they are pretty open . . . he/she/they just talks to us and his/her/their friends at school . . . his/her/their sister is his/her/their rock.” Nearly 16% of all patient responses included their healthcare team as a major source of support. “I have a good support team, but mainly it’s the people at the hospital, the doctors and nurses, the people I’ve had on my team since like two (years old).”

Coping mechanisms

Both patient (9/19, 47%) and caregiver (9/21, 43%) respondents reported that adolescents and young adults with heart failure mostly cope through hobbies, music, art, and activities. “Music and puzzles, poetry, anything that allows me to express my emotions and I think puzzles are . . . it allows me to turn my brain off. So, it allows me to forget that I’m in the hospital or I’m sick or something like that,” one patient responded. Notably, three adolescent and young adult participants endorsed having no coping skills while

one said, “I just push those feelings away.” Only one caregiver perceived their child to have no coping skills.

Resilience among adolescents and young adults with heart failure and their caregivers

Resilience defined

Initially, half of the patient respondents were unable to define resilience; however, after a definition was provided by the interviewer, all understood the term and were able to discuss their viewpoints and experiences specific to resilience (Table 3). Most (5/10, 50%) patient reflections on the term focused on “strength, fighting, and sticking with it”. Two reflected on their definition of resilience, “. . . somebody who can bounce back from a lot of stuff, someone who’s, who’s been through a lot of stuff but also they know that it’s just another obstacle in the road” and “. . . not letting things get to you or being strong.”

Examples of resilience

Both patients and their caregivers were prompted to reflect on a time during which the adolescents and young adults demonstrated resilience. Nearly all patient and caregiver responses focused on an experience related to a medical therapy, surgery, or hospitalisation. When asked to recall a time their child demonstrated resilience, “always” was a noteworthy response among caregivers of adolescents and young adults with heart failure (3/11, 27%).

Final advice to others

Patients were questioned about how other individuals with a similar heart condition to theirs could foster and build resilience. All patients were able to provide responses, with the majority of them focused on remaining positive and optimistic (7/14, 50%), which in turn would build resilience. Two patients recommended, “. . . just live how you want to” and “. . . just stay the course. It’s a tough road but in the end I’m very normal.” Seeking family and peer support was another common theme that adolescents and young adults reported as a way to build resilience. Patients were lastly asked for any final advice from others who are experiencing similar journeys (Table 3), with one patient summarising their experience, “It gets easier, it gets easier. After a while you kind of just, it becomes your normal routine. It’s a part of our life, it’s the life we were dealt, and it was the cards we were dealt and we have to play the hand we were given. It’s going to take a long time, it’s going to be a long road but it gets easier . . . a lot easier.”

Discussion

Adolescents and young adults with heart failure face a variety of challenges, both medically and psychosocially. While risks for both medical and psychological comorbidities are high among this patient population, we also know negative outcomes are not ubiquitous.^{2,3} It is important to increase the understanding of promotive and protective factors with regards to psychological health, particularly given associations between mental health and cardiac outcomes.^{4,5} To our knowledge, this is the first study among a racially and socioeconomically diverse sample of adolescents and young adults with heart failure and their caregivers to gain insight into how they view their own personal challenges, difficulties, coping skills, and resilience through qualitative methods.

In the current study, patients often defined resilience as “being strong,” “bouncing back,” and “persevering through any situation.”

Patients generally had positive thoughts about the term and were often able to describe times that they demonstrated resilience throughout their medical journey, which is similar to findings supported by a recent qualitative study on resilience in adult CHD patients.³⁷ Perhaps most notably, findings demonstrated that a majority of adolescents and young adults with heart failure are, by their own definition, resilient, with more than half indicating that living with advanced heart disease causes little or no difficulties in their life. This finding is supported by a recent study which demonstrated that individuals living with CHD scored higher on a commonly used measure of resilience when compared to their healthy counterparts.²⁸ Similar findings were seen in a cohort of children and adolescents with chronic kidney disease with resilient outcomes being similar between those with chronic kidney disease and their healthy controls.³⁸

Prior research on the concept of post-traumatic growth, or the positive psychological change that can occur in the face of a traumatic event, may provide insight into the current study findings.^{39–41} In our study, patients and their caregivers were able to easily recall a time during which they were resilient, and in almost all cases, the ‘identifiable event’ was related to a medical procedure or adverse event. This begs the question as to whether those who experience a traumatic health-related event, which many of the study patients described, can in turn, develop positive coping strategies and resilience-building processes. In adolescents and young adults with cancer, post-traumatic growth was observed in many subjects as a result of cancer-related stressors.^{39–41} The authors of this study posited that these events may partially foster resilient processes and outcomes, in comparison to other ‘healthy’ individuals, who may not experience such events.

Caregivers of study patients, in contrast, perceived their child with heart failure as experiencing higher overall heart disease-related burden and disease-specific worries and difficulties. This finding has been supported by others who demonstrated discrepancies in youth and parent reports of psychosocial quality of life and emotional health. Patel and colleagues revealed that among children with CHD, lower parent–child agreement was observed specific to emotional functioning, internalising behaviors, and anxiety, similar to our findings.⁴² In other samples of children and teenagers with CHD, discrepancies between patient–parent dyads in specific indices, such as psychosocial quality of life and emotional functioning, have been observed.^{43,44} Further, significant discrepancies were noted between what adolescents and young adults with heart failure desired in terms of their healthcare communication and medical decision-making compared to what their parents perceived they wanted, perhaps suggesting that many patients with advanced heart disease “can handle more” than adults in their life may perceive.³⁴

Among both patients and caregivers in our study, a support structure was identified as an important component to adolescent and young adult coping and resilience building. The significance of a support structure and its positive impact on resilience has been studied heavily, both in caregivers of medically complex children^{23,24} and in patients with CHD.^{26–28} In patients with CHD, peer support has been identified as an unmet need for a subset of patients.^{45,46} Few respondents in our study noted patients as having unhealthy or no identified coping skills. For many, coping strategies often included engagement in hobbies, music, drawing, and art. Survey-based studies have reported interest among young people with heart disease in coping and stress

management information/education. In a large international survey of 1,200 patients with CHD and their caregivers, one in three stated that materials specific to promoting their own mental health and coping would be helpful.⁴⁵ This has been seen in adults living with CHD as well, with a recent study reporting 1/3 of study respondents had interest in coping and managing stress related to their heart disease.⁴⁶

Patients were given the opportunity to provide any final thoughts and advice to other patients and caregivers who are navigating the paediatric heart failure journey. Optimism and positivity were common themes among the responses. This finding is analogous to that reported in a recent qualitative study of resilience in adult CHD patients, where themes such as purpose and gratitude commonly emerged among study participants.³⁷

Despite recently published findings on the importance of resilience and positive psychological influences among children and young adults with heart failure, no intervention programmes exist at this time to promote resilience or positive well-being in this at-risk population. Among other chronic disease processes, implementation of such programmes has shown promise.^{47–49} Within the adult congenital cardiac community, psychosocial interventions have been deemed feasible and potential benefits to individuals’ mindfulness and coping^{50,51} has been demonstrated. Results of this qualitative study underscore the importance of community/social support, hobbies (i.e., passion and purpose), optimism, and gratitude in terms of patient coping and resiliency building. Building upon these findings, Cousino *et al.* recently described the development of the WE-BEAT well-being education programme, which utilises the principles of community, mindfulness and relaxation, purpose and identity, adjustment, and self-gratitude, to foster resilience in paediatric heart disease (52). Although further research is needed to demonstrate the psychological impact of these programmes, we hope that the findings of this current manuscript can provide further insight into the needs of paediatric heart failure patients as it relates to well-being and resilience intervention programmes.

While the present findings can inform future studies and intervention design, we acknowledge several study limitations. Our interviews were conducted with patients and caregivers from a single paediatric heart failure centre in the Midwest. As a result, despite our notable representation of participants across racial/ethnic and socio-economic strata, as well as high representation of paternal caregivers, our results may not be as generalisable in comparison to multi-center, multi-national studies. Heart failure is a heterogeneous diagnosis with a vast range of illness severity, treatment, and disease course. Some of our patient participants were admitted and actively awaiting heart transplant, while others were followed outpatient and prescribed one or two heart failure medications. As such, the heart journey experiences of the participants likely varied a great deal. Illness severity and treatment course were not considered in terms of qualitative analysis. Additionally, the study site has integrated mental health services, including psychology, social work, and child life, for patients with heart disease, and all patients requiring advanced cardiac therapies (i.e., ventricular assist device, transplant) meet with psychology and social work as a standard of care. The role of these psychological supports on patient-reported data in this study is not easily parsed out. Findings may be different across centres or patient populations where there is less access to preventative and promotive mental health care. Lastly, this study was performed in

the midst of the SARS-CoV-19 pandemic, a time during which the lives of young people living with heart disease was greatly impacted.⁴⁵ This may have impacted results.

Despite limitations, this research serves as a foundation for future studies of both risk and resilience specific to psychological well-being in paediatric advanced heart disease. This study adds diverse patient and caregiver voices to this field of science while also emphasising psychosocial experiences at advanced stages of paediatric heart disease, as opposed to focusing on specific diagnostic or lesion groups. Overall, adolescent and young adult patients in our study did not view their life as significantly burdened by their heart failure, especially when compared to parental perceptions. Social support, particularly in family and friends, and positive coping skills, such as maintaining optimism, were noted by most in the study. While it remains critical that mental health morbidity is addressed and mitigated in paediatric heart disease, interventions focussed on identifying, enhancing, and fostering resilient processes and outcomes for both patients with heart disease and their caregivers are the exciting next step for the field.

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References

- Shaddy RE, George AT, Jaeklin T et al. Systematic literature review on the incidence and prevalence of heart failure in children and adolescents. *Pediatr Cardiol* 2018; 39: 415–436.
- Peng DM, Rosenthal DN, Zafar F, Smyth L, VanderPluym CJ, Lorts A. Collaboration and new data in ACTION: a learning health care system to improve pediatric heart failure and ventricular assist device outcomes. *Trans Pediatr* 2019; 8: 349–355.
- Cousino MK, Lim HM, Smith C et al. Primary disease, sex, and racial differences in health-related quality of life in adolescents and young adults with heart failure. *Pediatr Cardiol* 2022; 43: 1568–1577.
- Levine GN, Cohen BE, Commodore-Mensah Y et al. Psychological health, well-being, and the mind-heart-body connection: a scientific statement from the American Heart Association. *Circulation* 2021; 143: e763–e783.
- 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: e000110.
- Gleason LP, Deng LX, Khan AM et al. Psychological distress in adults with Congenital Heart Disease: focus beyond depression. *Cardiol Young* 2019; 29: 185–189.
- Gupta S, Giuffre RM, Crawford S, Waters J. Covert fears, anxiety and depression in Congenital Heart Disease. *Cardiol Young* 1998; 8: 491–499.
- Bromberg JI, Beasley PJ, D'Angelo EJ, Landzberg M, DeMaso DR. Depression and anxiety in adults with Congenital Heart Disease: a pilot study. *Heart Lung* 2003; 32: 105–110.
- Marino BS, Lipkin PH, Li et al. Neurodevelopmental outcomes in children with Congenital Heart Disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012; 126: 1143–1172.
- Kovacs AH, Bandyopadhyay M, Grace SL et al. Adult Congenital Heart Disease-Coping And REsilience (ACHD-CARE): rationale and methodology of a pilot randomized controlled trial. *Contemp Clin Trials* 2015; 45: 385–393.
- Kovacs AH, Saidi AS, Kuhl EA et al. Depression and anxiety in adult Congenital Heart Disease: predictors and prevalence. *Int J Cardiol* 2009; 137: 158–164.
- Kovacs AH, Sears SF, Saidi AS. Biopsychosocial experiences of adults with Congenital Heart Disease: review of the literature. *Am heart J* 2005; 150: 193–201.
- Rea KE, McCormick AM, Lim HM, Cousino MK. Psychosocial outcomes in pediatric patients with ventricular assist devices and their families: a systematic review. *Pediatr Transplant* 2022; 25: e14001.
- Cousino MK, Schumacher KR, Rea KE et al. Psychosocial functioning in pediatric heart transplant recipients and their families. *Pediatr Transplant* 2018; 22: e13110.
- Biber S, Andonian C, Beckmann J et al. Current research status on the psychological situation of parents of children with Congenital Heart Disease. *Cardiovasc Diagn Thera* 2019; 9: S369–S376.
- Soulvie MA, Desai PP, White CP, Sullivan BN. Psychological distress experienced by parents of young children with Congenital Heart Defects: a comprehensive review of literature. *J Soc Serv Res* 2012; 38: 484–502.
- Maxwell GM, Gane S. The impact of Congenital Heart Disease upon the family. *Am Heart J* 1962; 64: 449–454.
- Brosig CL, Mussatto KA, Kuhn EM, Tweddell JS. Psychosocial outcomes for preschool children and families after surgery for complex Congenital Heart Disease. *Pediatr Cardiol* 2007; 28: 255–262.
- SL Docherty, Miles MS, Holditch-Davis D. Worry about child health in mothers of hospitalized medically fragile infants. *Adv Neonatal Care* 2002; 2: 84–92.
- Strange G, Stewart S, Farthing M et al. Living with, and caring for, Congenital Heart Disease in Australia: insights from the Congenital Heart Alliance of Australia and New Zealand online survey. *Heart lung Circ* 2020; 29: 216–223.
- Connor KM, Davidson JRT. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003; 18: 76–82.
- Rosenberg AR, Yi-Frazier JP. Commentary: resilience defined: an alternative perspective. *J Pediatr Psychol* 2016; 41: 506–509.
- Lau N, Yi-Frazier JP, Bona K, Baker KS, McCauley E, Rosenberg AR. Distress and resilience among adolescents and young adults with cancer and their mothers: an exploratory analysis. *J Psychosoc Oncol* 2020; 38: 118–124.
- Rosenberg AR, Wolfe J, Bradford MC et al. Resilience and psychosocial outcomes in parents of children with cancer. *Pediatr Blood Cancer* 2014; 61: 552–557.
- 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: 49–53.
- Silva AM, Vaz C, Areias MEG et al. Quality of life of patients with Congenital Heart Diseases. *Cardiol Young* 2011; 21: 670–676.
- Teixeira FM, Coelho RM, Proença C et al. Quality of life experienced by adolescents and young adults with Congenital Heart Disease. *Pediatr Cardiol* 2011; 32: 1132–1138.
- Glenn T, Cousino MK, Wernovsky G, Schuchardt EL. Resilient hearts: measuring resiliency in young people with Congenital Heart Disease. *J Am Heart Assoc* 2023; 12: e029847.
- T Verma, Rohan J. Examination of transition readiness, medication adherence, and resilience in pediatric chronic illness populations: a pilot study. *Int J Env Res Pub He* 2020; 17: 1905.
- Carlsen K, Haddad N, Gordon J et al. Self-efficacy and resilience are useful predictors of transition readiness scores in adolescents with Inflammatory Bowel Diseases. *Inflamm Bowel Dis* 2017; 23: 341–346.
- Yi-Frazier JP, Yaptangco M, Semana S et al. The association of personal resilience with stress, coping, and diabetes outcomes in adolescents with type 1 diabetes: variable- and person-focused approaches. *J Health Psychol* 2015; 20: 1196–1206.
- Etikan I. Comparison of convenience sampling and purposive sampling. *Am J Theor Appl Stat* 2016; 5: 1.
- Cousino MK, Miller VA, Smith C et al. Medical and end-of-life decision-making preferences in adolescents and young adults with Advanced Heart Disease and their parents. *JAMA Netw Open* 2023; 6: e2311957.

34. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15: 1277–1288.
35. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl* 1965; 12: 436–445.
36. Steiner JM, Abu-Rish Blakeney E, Corage Baden A et al. Definitions of resilience and resilience resource use as described by adults with Congenital Heart Disease. *Inter J Cardio Cong Heart Dis* 2023; 12: 100447.
37. Moreira JM, Bouissou Morais Soares CM, Teixeira AL, AC Simões e Silva, Kummer AM. Anxiety, depression, resilience and quality of life in children and adolescents with pre-dialysis chronic kidney disease. *Pediatr Nephrol* 2015; 30: 2153–2162.
38. Yi J, Zebrack B, Kim MA, Cousino M. Posttraumatic growth outcomes and their correlates among young adult survivors of childhood cancer. *J Pediatr Psychol* 2015; 40: 981–991.
39. Zebrack B, Kwak M, Salsman J et al. The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psychooncology* 2015; 24: 162–168.
40. Greup SR, Kaal SEJ, Jansen R et al. Post-traumatic growth and resilience in adolescent and young adult cancer patients: an overview. *J Adolesc Young Adul* 2018; 7: 1–14.
41. Patel BJ, Lai L, Goldfield G, Sananes R, Longmuir PE. Psychosocial health and quality of life among children with cardiac diagnoses: agreement and discrepancies between parent and child reports. *Cardiol Young* 2017; 27: 713–721.
42. Uzark K, Jones K, Slusher J, Limbers CA, Burwinkle TM, Varni JW. Quality of life in children with heart disease as perceived by children and parents. *Pediatrics* 2008; 121: e1060–e1067.
43. Berkes A, Pataki I, Kiss M et al. Measuring health-related quality of life in hungarian children with heart disease: psychometric properties of the hungarian version of the pediatric quality of life Inventory™ 4.0 Generic core scales and the cardiac module. *Health Qual Life Out* 2010; 8: 14.
44. Cousino MK, Pasquali SK, Romano JC et al. Impact of the COVID-19 pandemic on CHD care and emotional wellbeing. *Cardiol Young* 2021; 31: 822–828.
45. Kovacs AH, Bendell KL, Colman J, Harrison JL, Oechslin E, Silversides C. Adults with Congenital Heart Disease: psychological needs and treatment preferences. *Congenit Heart Dis* 2009; 4: 139–146.
46. Rosenberg AR, Bradford MC, McCauley E et al. Promoting resilience in adolescents and young adults with cancer: results from the PRISM randomized controlled trial. *Ann Ny Acad Sci* 2018; 124: 3909–3917.
47. Rosenberg AR, Yi-Frazier JP, Eaton L et al. Promoting resilience in stress management: a pilot study of a novel resilience-promoting intervention for adolescents and young adults with serious illness. *J Pediatr Psychol* 2015; 40: 992–999.
48. Steineck A, Bradford MC, Lau N, Scott S, Yi-Frazier JP, Rosenberg AR. A psychosocial intervention's impact on quality of life in AYAs with cancer: a post hoc analysis from the promoting resilience in stress management (PRISM) randomized controlled trial. *Children* 2019; 6: 124.
49. 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: 766–773.
50. Luberto CM, Wang A, Li R, Pagliaro J, Park ER, Bhatt A. Videoconference-delivered mind-body resiliency training in adults with Congenital Heart Disease: a pilot feasibility trial. *Inter J Cardio Cong Heart Dis* 2022; 7: 100324.
51. Cousino MK, Dusing CR, Rea KE et al. Developing the WE BEAT well-being education programme to foster resilience and build connection in Paediatric Heart Disease. *Cardiol Young* 2024; 1–7.