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Review

# Psychological resilience: Significance for pediatric and adult congenital cardiology

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ABSTRACT

While the survival of children with congenital heart disease to adulthood has increased over the years, few are considered cured and most continue living with chronic disease, facing lifelong challenges. Psychological resilience is a dynamic process that can be acquired and modified, reflects an interaction between internal and external risk and protective factors, and can be defined as one's ability to face adversity in ways that may preserve well-being and quality of life. Resilience correlates with both physical and psychological outcomes, as individuals with greater resilience tend to experience more positive emotions, engage in more physical activity, and have improved physical functioning. In congenital heart disease, fostering resilience is important not only for adults, adolescents, and children, but also for parents of affected children. Promoting positive protective factors, particularly self-efficacy, self-esteem, humor, optimism, and positive affect, is important throughout the lifespan of patients with congenital heart disease. Resilience can be the focus of structured interventions and may also be fostered during regular clinical encounters by all members of the care team.

## 1. Introduction

Congenital heart disease (CHD) is the most common cause of congenital anomalies worldwide. The birth prevalence of CHD is approximately 9 per 1000 live births, accounting for 1.35 million children born with CHD every year worldwide and approximately 40,000 in the United States [1–3]. With advances in surgical techniques and continued improvements in management and care, the survival of children with CHD to adulthood has increased steadily over recent decades. At approximately 1.3 million in the United States, the number of adults living with CHD now accounts for about 60% of the total CHD population [3]. Only a minority of patients with CHD are considered cured, whereas most continue living with chronic disease, facing the potential of physical and psychological challenges throughout their lives, with significantly higher rates of cardiac and non-cardiac complications and mortality compared to the general population [4,5]. In addition to arrhythmias, heart failure, and repeat hospitalizations and procedures, adolescents and adults living with CHD also have a higher prevalence of mood and anxiety disorders that often go untreated [6–8]. They may experience difficulties in daily life affecting their peer relationships, employment, progression into independent adulthood, and overall quality of life [9–12]. For all of these reasons, it is therefore important that we help patients develop effective coping skills, engage in self-care behaviors throughout their lives, and maximize resilience to preserve their overall health and quality of life [13,14].

In this review article, we first define psychological resilience in general and medical populations. We next focus on what is known about resilience in CHD, in both the pediatric setting (parents, children, and adolescents) and among adults. Lastly, we describe potential ways of improving resilience in patients and their families.

## 2. What is psychological resilience?

### 2.1. Defining resilience

Current understanding of psychological resilience partially arose from the field of child development, in which it was observed, perhaps unexpectedly, that some children who experienced adverse situations were found to nonetheless sustain positive functioning and development in certain domains [15]. Many definitions of resilience have emerged since then, with some focusing more on individual personality traits and others describing it as more of a dynamic process that is dependent on interactions between the individual and their environment [16,17]. In general, resilience refers to the ability to "navigate adversity in a manner that protects health, well-being, and life satisfaction." [18] It is a way of responding to various stressors, such as

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injuries, interpersonal struggles, tragic events, work-related challenges, and disease, with the aim of reducing negative effects of the stressor and returning to normal performance when possible [19,20]. It has been described synonymously with adaptability, reduced vulnerability, and effective coping [21–24]. As a construct, resilience depends on personal, cultural, and situational factors. That is, it is possible that one may be resilient in one specific situation, but not necessarily in another [19]. Likewise, resilience can change over one's lifetime and thus remains an important concept from childhood through older adulthood [25].

### 2.2. Protective and risk factors

A number of protective factors and risk factors associated with resilience have been described. Protective factors include positive emotions, having a sense of meaning and satisfaction with life, optimism, social support including positive role models, exercise, humor and an active coping style [13,16,26]. Risk factors associated with lower levels of resilience and greater likelihood of maladaptation include negative affect, depression, anxiety, higher levels of perceived stress, and post-traumatic stress disorder [16]. In a large meta-analysis studying the effects of protective, risk, and demographic factors on resilience, it was concluded that, in general, protective factors had large effect sizes and risk factors had medium effect sizes [16]. These findings support the idea that resilience reflects positive individual traits and meaningful interpersonal relationships, and that perhaps an effective approach to improving one's resilience may be to enhance positive protective factors rather than target negative risk factors. This becomes particularly important in the face of chronic illness, where one might be unlikely to greatly alter the course or outcome of the illness itself, yet may be able to adapt their approach and coping style to preserve an acceptable quality of life and even exhibit personal growth.

### 2.3. Resilience and health outcomes

Resilience scores have been shown to correlate with both physical and psychological outcomes. Individuals with higher levels of well-being have demonstrated less inflammation, lower levels of cortisol secretion, lower likelihood of disability, and better management of changes in health status [27–29]. Adults with higher resilience levels engage in more physical activity, have improved physical functioning, and fewer limitations in activities of daily living associated with aging. In general, patients with chronic physical illness report lower levels of resilience than healthy individuals [19]. When faced with a new medical condition, those with higher levels of resilience experience lower levels of disability, suggesting that resilience modifies the relationship between the two [28,30].

Individuals with greater resilience tend to exhibit less catastrophizing behavior and experience more positive emotions [31]. In patients with cancer, resilience has been shown to have a positive effect on quality of life and recovery that seems related to having a life purpose, psychological and social adaptation, and positive coping during stressful situations [32]. Similarly, resilient individuals may manifest quicker recovery from the negative effects of pain and can sustain positive functioning [25]. Interestingly, when examining the levels of resilience in various types of chronic disease states, research suggests that the more serious the disease, the higher the patients' resilience, perhaps in an effort to reduce the negative effects and preserve a degree of control and quality of life [19].

In summary, resilience is a dynamic process that can be acquired and modified throughout one's lifespan, including among individuals with chronic illnesses and diminished physical health status. It is dependent on an interaction between internal and external factors and helps individuals respond, cope, and adapt to stress in an effort to preserve quality of life. It thus carries significant relevance for individuals affected by CHD, which often presents physical and psychological challenges across the lifespan.

## 3. Resilience in congenital heart disease

### 3.1. Parents

Having a child with CHD understandably often affects the well-being of the entire family. Studies have shown that parents of children with CHD experience higher levels of stress, depression, anxiety, hopelessness, and perceived vulnerability [33–37]. In general, families who have fewer psychosocial resources and less social support are at an increased risk of psychological distress over time [38]. Further, families with less understanding of the specific CHD diagnosis and less cohesiveness tend to experience more distress [39]. Elevated parental stress tends to begin at the time of diagnosis, which is often made prenatally, and continues through the birth and initial hospitalization. As adaptation and coping skills develop, stress levels may subside somewhat, but can return in a cyclical pattern with each hospitalization, procedure, or cardiac surgery [34,36].

Gender-specific outcomes have been observed in parents of children with CHD. A study of mothers found that while their joy and life satisfaction remained relatively unaffected, they exhibited higher feelings of anger and frustration over the first 6 months of their child's life [40]. As compared to fathers, mothers of children with CHD tend to experience higher levels of anxiety, hopelessness, distress, and somatic symptoms [35,37,39,41]. The severity of CHD has also been shown to correlate with parental distress levels, with parents of children with more complex CHD exhibiting higher levels of distress over time [42]. A recent large study of parents of more than 1200 school-age children in the United Kingdom and the United States concluded that more complex CHD was associated with poorer long term parental psychosocial outcomes, particularly higher levels of anxiety and depression, whereas parents of children with milder forms of CHD had significantly lower levels of illness-related stress and post-traumatic stress [43].

With the understanding that resilience is a mediator between stress perception and stress response, it is important to help parents and families identify their existing coping skills and provide them with additional resilience resources and support [34,38]. Factors such as familial cohesiveness and adaptive coping style are instrumental in successful adaptation to parenting a child with CHD and can be targeted in future interventions, along with normalizing and managing parental anxiety [38].

A recent systematic review of psychological interventions for those affected by CHD identified only five studies that targeted parents, predominately mothers [44]. Three of the five studies showed some improvements in psychological outcomes. One parent-infant intervention targeted parenting skills and maternal adjustment, with resultant reduction in maternal worry and anxiety, improvements in coping and adjustment, and higher rates of breastfeeding [45]. Similarly, improvements in maternal general mental health and family functioning were observed following implementation of a school readiness program for families of school-age children with CHD [46]. Another study implemented a surgery preparedness program that included information and coping skills training and observed improvements in caregiver confidence in their ability to care for their children in the hospital and at home [47]. Although these intervention programs did not specifically target resilience, they did address known resilience protective factors. Given the paucity of data and heterogeneity of the intervention programs, further research with robust methodology and comprehensive outcomes assessment tools is needed to determine whether and how structured interventions can improve the resilience of parents with infants and children with CHD.

### 3.2. Children and adolescents

As a group, children and adolescents with CHD experience more

depressive symptoms and behavioral issues than their peers [48–50]. One study of adolescents with CHD who were generally asymptomatic from a functional class perspective found that 9% of the cohort scored higher than the cutoff for depression and 27% met the anxiety cut-off score on a self-report questionnaire [51]. Moreover, none of the adolescents with elevated symptoms had undergone mental health assessment or treatment [51]. A systematic review of psychological adjustment and quality of life among children and adolescents with CHD found that up to 41% of children experience psychological maladjustment [52]. In a recent systematic review and meta-analysis, 25% of children and adolescents with CHD were found to demonstrate significant internalizing and/or externalizing behavioral difficulties [50]. Although the percentages vary across these studies, it seems reasonable to conclude that between one-quarter and one-third of children and adolescents with CHD experience elevated psychological symptoms, which in turn are known to be associated with lower resilience.

Much of the research that has investigated resilience in the CHD pediatric setting has come from Korea. Across these studies focused on adolescents with CHD, higher resilience scores were associated with several factors including being a boy, less complex disease, higher economic status, and lower depression symptoms [48,53]. Korean adolescents with CHD have also been shown to exhibit the highest level of resilience when using task-oriented coping (e.g., seeking information and solving and restructuring problems) [14]. As coping skills can be taught and modified, CHD researchers and clinicians can develop educational programs and other supportive interventions in an effort to increase patient resilience.

Unfortunately, there are limited data regarding the assessment of resilience and resilience intervention programs in children and adolescents with CHD. A recent systematic review identified two psychosocial interventions developed for children and adolescents; one targeted depression and stress and the other targeted resilience [44]. A surgery preparedness program showed improved cooperation during hospitalization, better adjustment at home after discharge, and faster improvement of functional status; however, it had no effect on anxiety [47]. Similarly, a mindfulness-based stress reduction program reduced illness-related stress, but did not have a significant effect on depression or anxiety [54]. A resilience improvement program for adolescents with CHD targeted psychosocial protective factors including positive emotions, cognitive flexibility, meaning, social support, and an active coping style; adolescents in the experimental group showed an increase in resilience level although there was no impact on quality of life [13].

One of the studies from Korea demonstrated that higher levels of resilience in adolescents with CHD were correlated with positive parental rearing behaviors (e.g., emotional warmth) and lower resilience scores were associated with negative parental rearing behaviors e.g., rejection, punishment, and overprotection [53]. These results highlight the importance of attending to parental coping and parenting skills, as this may improve both parental well-being and adolescent resilience.

### 3.3. Adults

A meta-analysis of twenty-two studies in which adolescents and adults with CHD completed self-reported measures of emotional functioning concluded that patients did not differ from their peers, although significant heterogeneity was observed. [55] In contrast, other studies that have utilized clinical interview methodology have observed that approximately one third of adults with CHD experience mood and anxiety disorders that often go untreated [6–8,56]. The results of one study demonstrated that many patients experience a higher level of situational anxiety in the setting of being at the hospital [57]. It must be stated that results are not consistent around the globe. In particular, research from the Netherlands is suggestive of positive psychological outcomes and emotional functioning among adults with CHD, with patients having more favorable scores on personality traits such as self-esteem, hostility, and neuroticism [58–60].

Despite general evidence indicating that, as a group, patients with chronic physical illnesses appear to have lower resilience compared to healthy controls, [19] a Korean study observed that adults with CHD reported higher levels of resilience than healthy control subjects [61]. Although we cannot make generalizations based upon a single study, one might postulate that this finding might at least partially reflect the fact that patients with CHD have had their disease their entire life and thus have an opportunity to develop effective coping skills, positive adaptation, and resilience from an early age [62]. Moreover, in this study, those who identified as religious also reported higher levels of resilience and better quality of life. After adjusting for depression and anxiety, an interaction between initial disease severity and psychological resilience was noted, suggesting that adults with CHD might develop greater resilience in response to severity of their initial diagnosis. Two Portuguese studies showed that social support had an impact on increasing resilience in patients with CHD, as those with better social support had a better quality of life across all dimensions [62,63]. However, data are limited and highly heterogeneous, and one should be mindful of making generalized conclusions in the absence of more robust studies.

Perceived health status and social adjustment are known modifiable predictors of depression and anxiety in this patient population and can thus be a focus of intervention [7]. Targeted psychological intervention integrated within the clinical setting has been shown to reduce psychological distress in adults with CHD, thus presumably also having a positive impact on resilience and quality of life [64]. Two intervention studies targeting psychosocial outcomes and/or resilience in adults with CHD have recently been published. From Canada, a pilot randomized controlled trial of an 8-session psychosocial intervention for adults with CHD found the program to be highly valued among participants and, although not powered for efficacy, showed a medium effect size in favor of the intervention group for depressive symptoms [8]. This intervention, administered in a group setting, included education about living with CHD, cognitive-behavioral coping skills, social interaction and communication skills, relaxation training, and strategies to improve sleep. In the second study from Korea, a 6-week self-management efficacy promotion program showed a significant improvement in disease-related knowledge and self-management performance in adults with CHD, although health-related quality of life was not significantly different between intervention and control groups [65].

### 3.4. Opportunities to foster resilience

Despite some encouraging preliminary results, a recent systematic review found limited evidence of the efficacy of psychological interventions for children and adults with CHD, thus exposing the need for more robust research in this area [44]. It thus becomes appropriate to review the broader literature surrounding resilience interventions. A 2014 meta-analysis of 25 randomized trials of resilience interventions across diverse samples concluded that outcomes tended to favor participation in the interventions, although the trials were at moderate to high risk of bias [66]. A more recent meta-analysis of resilience improvement programs for patients with chronic disease identified methodological challenges in determining effects of resilience interventions on depression, anxiety, and quality of life [32]. Not surprisingly, a systematic review of the methodology of 43 randomized controlled trials of resilience interventions found significant heterogeneity and problems in the concepts, methods, and designs of the studies, along with lack of a consistent definition of resilience and variability in outcome measures [67]. In order to overcome these challenges, the authors proposed an outcome-oriented definition and assessment of resilience, along with methodological standards for future intervention studies.

Given the physical and psychosocial challenges that individuals with CHD face across their lifespan, as well as the paucity of mental health professionals integrated within health care teams, it is important

to consider strategies that can be implemented in the clinical setting by all members of the care team in hopes of enhancing resilience and quality of life. The dynamic and modifiable nature of resilience allows healthcare providers an opportunity to impact resilience in their patients throughout their lives.

In the pediatric setting, it is important to educate and empower parents of children with CHD and to validate their emotions. The promotion of adjustment and effective coping strategies can lead to positive outcomes in mothers and infants as well as family functioning [45,46]. As parental factors can impact resilience in children, emotional warmth and secure attachment should be fostered and overprotection should be discouraged [53]. Education about the diagnosis as well as anticipatory guidance regarding hospitalizations, surgical and catheter procedures, and expected trajectories may help alleviate some anxiety for some parents. Family-centered interventions and support groups allowing parents to share their experiences with others can be helpful and should be offered. A multidisciplinary approach with the focus on holistic care of the entire family of a child affected by CHD is recommended, with the aim of strengthening the resilience of patients and their families [68].

Children and adolescents with CHD may feel isolated or different from their peers due to frequent hospitalizations leading to interruption of schooling and reduced participation in usual peer activities [48]. Child-life specialists can be particularly helpful during lengthy hospital stays by providing age- and developmentally-appropriate information, addressing anxiety, and arranging daily activities [68]. Social support, role models, and positive social interactions with healthcare providers, teachers, and peers can be extremely valuable. Empowering patients with information about their disease and encouraging developmentally appropriate autonomy and self-management skills can foster independence and resilience. For example, it is important for providers to address adolescent patients directly, preferably on their own for part of each clinic visit, and allow them to fully express themselves and ask questions. Some patients also benefit from having social connections with others with CHD, and they can thus be guided to local and national patient organizations.

Knowing that protective factors are more strongly correlated with resilience than negative risk factors, [16] it seems reasonable to encourage providers to focus on positive protective factors, particularly self-efficacy, self-esteem, humor, optimism, and positive affect. When interacting with adults with CHD, providers are encouraged to provide positive verbal reinforcement for all demonstrations of effective coping and resilience. Although not tested in clinical trials, it is hard to imagine benefits not occurring through encouraging and modeling a healthy lifestyle with regular exercise, adequate sleep, healthy nutrition, and stress management techniques. Providing disease-specific education in a way that is easy to understand and accept can increase knowledge and help foster ownership, autonomy, and self-management skills. In addition, clinical experience suggests the validation and normalization of physical and psychological challenges and emotional reactions as well as the maintenance of a strong patient-provider partnership can enhance general well-being and resilience of our patients.

## 4. Conclusions

Resilience has been defined in many ways, but generally refers to the ability to face adversity in a way that optimizes well-being and life satisfaction [18]. It is a dynamic and modifiable process that can change throughout the lifespan and is most strongly influenced by protective factors [16] and can thus be the focus of structured psychosocial interventions and also incorporated into most clinical interactions between patients and providers. Given achievements in reducing morbidity and mortality, the field of CHD is now able to direct attention and resources to address the psychosocial challenges of living with a lifelong chronic health condition and enhance patients' overall well-being. Healthcare providers now have the opportunity to collaborate in the effort to foster resilience in individuals born with CHD.

## Declaration of Competing Interest

None.

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