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Perceptions of Disease-Related Stress: A Key to Better Understanding Patient-Reported Outcomes among Survivors of Congenital Heart Disease

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INTRODUCTION

Congenital heart disease (CHD) ranges from small lesions requiring little or no medical intervention to extensive lesions necessitating multiple open-heart surgeries, limiting normal daily activities, and potentially causing premature death. The perceived stress associated with health care utilization, worry about future health and ramifications for relationships, academic or occupational functioning, and economic independence likely vary over time and between individuals. Stressors inherent to living with CHD have been qualitatively described¹, but neither quantified nor examined as varying across patient demographics or contributing to patient-reported outcomes (PROs). PROs, such as health-related quality of life (HRQoL) and emotional wellbeing are associated with mortality in other cardiovascular disease populations^{2, 3} and have been identified as vitally important for health outcomes^{4, 5}.

PROs among survivors of CHD have been inconsistent¹. The heterogeneity in lesion severity found within CHD may contribute to variability in the stressors experienced by survivors, including differences in functional impairment^{6, 7}. A measure of functional status, such as the New York Heart Association functional (NYHA) class rating, has recently been shown to account for more variability in patient perceptions of their emotional HRQoL than multiple common cardiovascular comorbidities, treatment modalities or other indicators of functional capacity⁸. The effect of functional impairment on PROs may be better elucidated by examining what aspects of CHD are more stressful for those who experience greater functional impairment.

PROs and perceptions of stress are also affected by other individual differences, such as age^{6, 9} and sex⁶. As survivors enter adulthood, they may experience fluctuations in health (e.g., additional interventions and the occurrence of morbidities, such as arrhythmias and heart failure)¹⁰, responsibilities and resources (e.g., job status, assumption of more financial responsibility)^{1, 11} and interpersonal relationships¹, further affecting physical and emotional wellbeing. Although meta-analytic evidence suggests that the risk for distress increases from childhood to adolescence¹², whether the level of distress for adults with CHD exceeds that of the general population is less clear¹³. Sex differences may also be an important consideration. Women with CHD report more functional limitations, while males are more likely to take a long-term medication and have a higher mortality rate after adjusting for age and lesion type¹⁴. Despite some of the experiential differences men and women may have living with CHD, other studies have not found sex differences on measures of emotional distress^{15, 16}.

The current study sought to (1) identify the types and degree of stress experienced by CHD survivors based on age, functional status and sex, (2) examine differences in PROs (i.e., emotional distress and HRQoL) by age, functional status and sex, and (3) determine the unique contribution of CHD-related stress to variability in PROs. Adolescents were hypothesized to report less perceived stress and better physical HRQoL than young adults with CHD. Individuals with impaired functional status were predicted to report more items as stressful, greater perceived stress, and poorer PROs than individuals with normal functional status. Lastly, higher perceived stress was hypothesized to be associated with poorer PROs.

METHODS

Participants and Procedures

Participants were recruited from outpatient cardiology clinics at two sites: a pediatric hospital and an adult hospital. The aim of the larger study was to examine disease knowledge and health behavior engagement among adolescent, emerging adult, and young adult CHD survivors. Individuals were eligible if they (a) had a structural congenital heart defect, (b) were 15 to 39 years of age, (c) were fluent in English, but excluded if they (d) had been diagnosed with a genetic syndrome or (e) had cognitive limitations that would prevent completion of self-report measures.

A measure of emotional distress was added to the study protocol after data collection was initiated at the pediatric institution, but before commencing recruitment efforts at the adult hospital. Those participants recruited from the pediatric hospital were re-contacted to complete the measure of emotional distress while participants were concurrently being recruited from the adult facility. Ultimately, 141 participants from the pediatric hospital were successfully re-contacted and consented, and of those, complete data was obtained on 113 participants. From the adult hospital, 95% of participants approached consented (n=76) with complete data obtained from 60 participants. In sum, 173 participants provided data on the measure of emotional distress. Participants completed self-report measures online at home or in clinic, and demographic and medical variables were abstracted from hospital and clinic

records. The study protocol and informed consent/assent procedures were approved by the Institutional Review Board.

Demographics and Medical Status—Participants self-reported sex, race/ethnicity, and years of education. New York Heart Association (NYHA) functional class was extracted from medical charts and used to classify participants into two functional status groups: normal functioning (NYHA = 1) and impaired functioning (NYHA > 1). NYHA class was dichotomized based upon a recent study identifying a significant difference in physical and emotional HRQoL between those with any functional impairment (NYHA > 1) and those without (NYHA = 1)⁸. Participants were also grouped according to age as adolescents (age 15–18), emerging adults (age 19–25) and young adults (age 26–39).

Patient-Reported Outcomes

Perceived Stress—The Response to Stress Questionnaire (RSQ)¹⁷, was adapted to include 13 stressor items specific to CHD. Participants were asked to rate the degree to which they experienced each item as stressful on a 4-point Likert scale (“Not at all,” “A Little,” “Somewhat,” and “Very”). For each participant, the 13 ratings were summed to create a total stress score. The CHD-specific stressors were pretested for face validity by 12 individuals with CHD of various ages (15–38 years) and cardiac lesion severities. During a cognitive interview, these individuals were asked about the wording of each stressor item and whether there were any stressors that were not included, after which adjustments were made to create the final items. The stressor items demonstrated good internal consistency (Cronbach’s $\alpha = 0.87$) in the current study.

Emotional Distress—The Youth Self-Report (YSR)¹⁸ and Adult Self-Report (ASR) measures were used for adolescents or emerging and young adults¹⁹ respectively. The reliability and validity of these measures has been well-documented^{18, 19}. For the current study, the Internalizing subscale was used. The YSR and ASR produce T scores with a mean of 50 and standard deviation of 10. T scores above 63 are in the clinical range and are above the 90th percentile.

HRQoL—The Medical Outcomes Study SF-36v2 assessed the impact of physical (PCS) and emotional (MCS) symptoms on daily living. Scale scores range from 0–100 with higher scores indicating better HRQoL. The SF-36v2 is a commonly used tool across the United States and Europe, including in CHD^{8, 20}, and has strong psychometric properties²¹. The current study has met recent recommendations set forth by Bratt & Moons for conducting HRQoL research in CHD²².

Plan of Analysis

Missing items for the self-report measures were imputed if 25% of the items were missing by using the average score of the remaining items. For those measures that have pre-specified instructions for handling missing items (e.g., SF-36v2 and YSR/ASR), directions were followed. For the SF-36v2, scale scores can be calculated using the average score of the remaining items in that scale if at least 50% of the items were completed.²¹

Differences among age categories (adolescents, emerging adults and young adults), functional status (NYHA = 1 and NYHA > 1) and sexes on ratings of stress (Not at all/A little stressful, Somewhat/Very stressful) for each stressor item of the RSQ were examined using Pearson chi-squares. Posthoc pairwise chi-squares determined which age categories differed from one another. For the stressor items pertaining to having a device or taking a cardiac related medication, only participants for whom those items were relevant were included in the analyses. The Benjamini and Hochberg procedure was used to control for the false discovery rate within sets of chi-squares (age categories, functional status and sex) to reduce the likelihood of Type 1 error²³. Age differences in total CHD-related stress, emotional distress (internalizing symptoms) and HRQoL (physical and emotional) were examined using a one-way ANOVA with Tukey posthoc tests, while differences between sexes and functional statuses were determined using T-tests. Linear regressions examined the contribution of perceived stress to PROs above and beyond age, functional status and sex.

RESULTS

Participants included 173 adolescents ($n = 35$), emerging adults ($n = 39$) and young adults ($n = 99$), with demographic characteristics and PROs means and standard deviations described in Table 1. Approximately one third of the sample experienced functional limitations.

Age, Functional Status and Sex Differences in CHD-Related Stress

Two items from the RSQ emerged as stressful for almost half of the participants, regardless of demographics and functional status, reflecting concerns about future health and having scars or other visible signs of past medical procedures (Table 2). For those who had a device ($n=31$), 64.5% identified having a device as somewhat/very stressful, and for those taking at least one cardiac-related medication ($n=112$), taking medication was not identified as stressful by most (83.0%). The lowest stress ratings were concerns about the need for medical procedures in the future, going to the doctor for appointments or tests, limitations at work or school, and sexual dysfunction.

Adolescents reported less total CHD-related stress than emerging or young adults ($F[2, 165] = 8.39, p < .001$) (Figure 1). As seen in Table 3, adolescents reported less perceived stress regarding future medical procedures, paying for healthcare, and concerns about sexual dysfunction than both emerging and young adults with CHD. Adolescents also reported less perceived stress than young adults on not fully understanding what is wrong with their heart, but did not differ from emerging adults.

Individuals with impaired functional status (NYHA > 1) reported more perceived stress than those with 'normal' functional status ($t[166] = -4.09, p < .001$) (Figure 1), as well as rated the majority of items as more stressful: having children or having healthy children; future medical procedures; paying for healthcare; medical appointments and tests; understanding what is wrong with their heart; communicating with friends and family about one's health; limitations at work or school; experiencing sexual difficulties (Table 3).

Men and women did not differ in perceived stress ($t[166] = -.67, p = .507$) (Figure 1). The only item for which men and women differed on perceived stress was taking medication,

such that women who took a cardiac-related medication reported more stress than men who took medication.

Age, Functional Status and Sex Differences in Patient-Reported Outcomes

Overall, sample means for PROs did not differ from the normative means or surpass clinical cutoffs. Furthermore, the proportion of participants who had scores in the clinical range for internalizing symptoms (14%) was similar to what was expected in the general population ($\chi^2 = 2.99, p = .084$; 17.2%). Differences in PROs can be seen in Figure 2. Young adults reported poorer emotional HRQoL as compared to adolescents ($F[2,166] = 3.34, p = .038$). Internalizing symptoms ($F[2,169] = .58, p = .561$) and physical HRQoL ($F[2,166] = 2.53, p = .083$) did not significantly vary between age categories. Lower levels of physical ($t[167] = 6.35, p = .001$) and emotional HRQoL ($t[167] = 3.92, p = .001$) were identified among those with impaired functional status, but no differences were found for internalizing symptoms ($t[170] = -1.83, p = .068$) between those with and without functional limitations. In comparing sexes, no differences were found for PROs (internalizing symptoms: $t[170] = -0.34, p = .732$; physical HRQoL: $t[167] = 1.56, p = .122$; emotional HRQoL: $t[167] = 1.18, p = .240$).

Multivariate Models Predicting Patient-Reported Outcomes

For all three PROs, perceived stress uniquely contributed to the variability above and beyond age, functional status and sex (Table 4). When perceived stress was entered into the model, functional class remained a significant contributor of variance for both physical and emotional HRQoL. Functional status did not uniquely account for variance in internalizing symptoms when simultaneously considering perceived stress.

DISCUSSION

The current study is the first to quantify disease-related perceived stress among adolescent and adult survivors of CHD, as well as examine the relationships between perceptions of stress, demographics and PROs. Participants experiencing any functional limitations (NYHA > 1) reported significantly higher levels of perceived stress and poorer HRQoL than those with no functional limitations. Perceived stress also accounted for unique variance above and beyond functional status for all PROs.

In accordance with study hypotheses, higher perceived stress was strongly associated with poorer PROs. Item-level analyses facilitated the identification of which stressors may be more/less important to different demographic groups. Adolescents reported less stress than both emerging adults and young adults, which based on item-level analyses, is likely due to less concern about future health, paying for healthcare, not understanding one's heart condition, and experiencing sexual dysfunction. Several factors may contribute to the identified differences between age groups. First, as participants age, their disease knowledge, including knowledge about future health risks as a consequence of having CHD, may improve²⁴. Having a better understanding of the risks present may contribute to perceived stress and emotional distress, though this has yet to be empirically tested. Second, as CHD survivors age, the repercussions of their disease, both physical and monetary, may

become more salient as symptoms present and/or the need for reintervention is more probable⁹. This is further reflected in the findings for functional status. Individuals who were experiencing some degree of symptom burden reported higher levels of perceived stress and identified the majority of the items as more stressful than those who had a normal functional status. While functional status changes as age progresses, the results from the current study suggest that functional impairment may play an important role in accounting for the differences found between age groups for stress and dimensions of HRQoL. Perceived stress also emerged as accounting for unique variance in PROs, above and beyond functional status. Therefore, stress should be examined in as a mechanism by which functional status negatively affects PROs in future longitudinal studies.

The current study also compared PROs to measure norms, which is of particular importance given the variability in PROs found in the literature^{13, 25}. Participants were prospectively recruited to represent survivors across three age ranges from either an adult or pediatric medical setting. Our findings suggest that on average, adolescents, emerging adults and young adults report similar outcomes to measure norms, and the proportion of individuals experiencing clinically meaningful levels of internalizing symptoms was similar to measure norms. These results are in line with a recent meta-analysis of emotional distress among adolescents and adult CHD survivors¹³.

Limitations of the current study should be noted. First, the study design was cross-sectional. Therefore, causal inferences cannot be made about the relationship between perceptions of stress and PROs, and within-subject change over time could not be assessed. Ideally, a longitudinal investigation would explore how perceptions of stress regarding one's disease evolve over time as individuals assume more responsibility for their healthcare, develop meaningful relationships and experience different sequela of their disease. Despite this limitation, the intentional recruitment of participants across distinct age categories facilitates the exploration of age as a factor in how PROs may change over time in the absence of longitudinal data. Second, there are additional medical factors that are likely significant contributors to PROs other than perceptions of stress and NYHA. NYHA has been shown to explain the most variability in emotional HRQoL in comparison to many other easily accessible medical factors, including traditional classification of disease severity (e.g., "simple," "moderate" and "complex")⁸ and highlights the significant impact that even mild functional limitations has on PROs. Factors, such as lesion severity, re-hospitalizations, and additional surgical interventions may also play an important role over time as survivors age and should continue to be examined in longitudinal designs.

In conclusion, identifying stressors unique to CHD survivors of different ages, functional status and sex may help clinicians appropriately address these concerns. For example, sexual dysfunction may not be broached by a patient, but could be concerning to a young adult CHD survivor. Furthermore, the current findings suggest that having even mild functional impairment may have significant consequences on emotional distress and HRQoL via increased perceptions of stress related to having CHD. Patients with functional status impairment can be identified early in the course of treatment and offered cognitive behavioral therapy (CBT) for stress management.

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Figure 1.
Differences in perceived stress by age, functional status and sex.
* p .05; ** p .01

Figure 2.

Differences in patient-reported outcomes by age, functional status and sex.

A., B., C.

* $p < .05$; ** $p < .01$; ‡The normative mean, which for the Short-Form 36 version 2 collapses across age (18+ years) and sexes; †T scores above 63 are in the 90th percentile of scores.

CHD = congenital heart disease; NYHA = New York Heart Association functional class;

HRQoL = health-related quality of life; RSQ = Responses to Stress Questionnaire; SF-36v2 = Short Form 36 version 2; Y/ASR = Youth/Adult Self-Report

Table 1

Sample characteristics.

Total Sample N = 173	
	Mean (SD) or Percentage
Age (years)	26.61 (7.27)
Adolescents (n = 35)	16.20 (1.21)
Emerging Adults (n = 39)	22.13 (2.19)
Young Adults (n = 98)	32.05 (3.72)
Sex (% male)	44.5%
Race (% Caucasian)	89.0%
Education (% completed or current)	
High School	55.5%
Post-High School/Trade	7.5%
College	25.4%
Graduate/Professional	11.6%
Lesion Severity	
Simple	29.1%
Moderate	40.7%
Complex	30.2%
NYHA Class	
1	70.5%
>1	29.5%
Perceived Stress (RSQ; n = 169)	23.61 (8.04)
Internalizing Symptoms (Y/ASR)	51.46 (13.43)
HRQoL (SF-36v2; n = 170)	
Physical (PCS)	49.25 (9.23)
Emotional (MCS)	49.80 (10.60)

HRQoL = health-related quality of life; MCS = Mental Component Scale; NYHA = New York Heart Association; PCS = Physical Component Scale; RSQ = Responses to Stress Questionnaire; SF-36v2 = Short Form 36 version 2; Y/ASR = Youth or Adult Self-Report

Table 2

Responses to stressor items from the Response to Stress Questionnaire (RSQ) adapted for congenital heart disease.[‡]

	Not at All/A Little Stressful	Somewhat/Very Stressful
A. Not knowing how my health will be in the future (<i>Future Health</i>)	56.4%	43.6%
B. Concerns about having children or whether my children will be healthy (<i>Children</i>)	71.9%	28.1%
C. Concerns about whether medical procedures may be needed in the future (<i>Future Care</i>)	85.2%	14.8%
D. Paying for healthcare (<i>Cost of Care</i>)	74.5%	25.5%
E. Not being able to do activities that other people my age do (<i>Activities</i>)	60.6%	39.4%
F. Going to the doctor for appointment or tests (<i>Appointments</i>)	84.5%	15.5%
G. Not fully understanding what is wrong with my heart (<i>Understanding</i>)	82.9%	17.1%
H. Having scars on my chest or other visible signs of past medical procedures (<i>Scarring</i>)	59.7%	40.3%
I. Communicating with family, friends, or romantic partners about my health and healthcare (<i>Comm</i>)	81.3%	18.7%
J. Limitations at work or school (<i>Work/School</i>)	84.6%	15.4%
K. Having a device, such as a pacemaker or implantable cardioverter defibrillator (ICD) (<i>Device</i>)	35.5%	64.5%
L. Having to take medications (<i>Medication</i>)	83.0%	17.0%
M. Experiencing sexual difficulties (<i>Sexual Dysfunction</i>)	87.1%	12.9%

[‡]The percentages reported for items K and L included only those participants who have a device (n = 31) and took medication (n = 112), respectively. For all other items, the sample size ranged from 167–171.

Table 3

Pearson chi-square results of the percentage of participants who endorsed each stressor item on the Response to Stress Questionnaire (RSQ) as “Somewhat/Very Stressful” within each age category, NYHA class and sex.

RSQ Item	Age			NYHA Class			Sex	
	Adolescents	Emerging Adults	Young Adults	χ^2	I	>I	Male	Female
A. Future Health	23.5%	46.2%	49.5%	7.04 *	40.5%	51.0%	37.3%	48.4%
B. Children	20.0%	33.3%	28.9%	1.69	19.0%	50.0%	26.3%	29.5%
C. Future Care	2.9%	17.9%	17.9%	4.99	10.8%	24.5%	12.0%	17.0%
D. Cost of Care	8.8%	28.9%	29.9%	6.21 *	19.3%	40.0%	31.1%	21.1%
E. Activities	22.9%	51.3%	40.6%	6.38 [†]	38.0%	42.9%	36.0%	42.1%
F. Appointments	2.9%	15.4%	20.2%	5.67	9.2%	31.3%	15.1%	16.0%
G. Understanding	2.9%	13.5%	23.7%	8.31 *	13.3%	26.5%	20.0%	14.9%
H. Scaring	23.5%	53.8%	40.6%	6.96 [†]	36.1%	50.0%	35.5%	44.1%
I. Comm	20.0%	28.2%	14.4%	3.52	14.9%	28.0%	15.8%	21.1%
J. Work/School	5.7%	15.4%	18.9%	3.44	8.3%	32.7%	14.5%	16.1%
K. Device [†]	0.0%	60.0%	70.8%	4.10	64.3%	64.7%	71.4%	58.8%
L. Medication [†]	6.3%	13.6%	18.9%	1.69	13.0%	20.9%	29.2%	6.3%
M. Sexual Dysfunction	0.0%	10.3%	18.8%	8.33 *	7.4%	26.5%	17.1%	9.6%
								2.11

[†]The sample size for the Pearson chi-square analyses ranged from 167–171 with the exception of items K and L, which included only those participants who have a device (n = 31) and took medication (n = 112), respectively.

[†]Results were no longer statistically significant after applying the Benjamini and Hochberg procedure to control family wise error.

*
p 0.05;

**
p 0.01

NYHA = New York Heart Association

Table 4

Linear regressions demonstrating the unique contribution of perceived stress to the variability in patient-reported outcomes.

	β (<i>p</i>)	R^2 (<i>p</i>)
Physical HRQoL		
Model 1		
Age	−0.11 (0.117)	
NYHA Class	−0.42 (<0.001)	
Sex	−0.06 (0.386)	
Model 2		
Age	−0.04 (0.580)	
NYHA Class	−0.33 (<0.001)	
Sex	−0.07 (0.304)	
Perceived Stress	−0.33 (<0.001)	
		0.09 (<0.001)
Emotional HRQoL		
Model 1		
Age	−0.14 (0.064)	
NYHA Class	−0.24 (0.002)	
Sex	−0.05 (0.476)	
Model 2		
Age	−0.02 (0.817)	
NYHA Class	−0.08 (0.253)	
Sex	−0.07 (0.295)	
Perceived Stress	−0.57 (<0.001)	
		0.28 (<0.001)
Emotional Distress		
Model 1		
Age	0.05 (0.543)	
NYHA Class	0.10 (0.198)	
Sex	0.04 (0.630)	
Model 2		
Age	−0.07 (0.287)	
NYHA Class	−0.05 (0.484)	
Sex	0.05 (0.498)	
Perceived Stress	0.56 (<0.001)	0.27 (<0.001)

HRQoL = health-related quality of life; NYHA = New York Heart Association