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Research

An exploration of psychological trauma and positive adaptation in adults with congenital heart disease during the COVID-19 pandemic

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Abstract
The growing population of adults with congenital heart disease (CHD) often have lifelong experience of dealing with potentially traumatic health crises and medical uncertainty whilst facing increased vulnerability to post-traumatic stress disorder (PTSD). The COVID-19 pandemic presents additional challenges for this population including increased risk of health complications, shielding and strict social distancing, changes to medical care provision and social stigma. Despite such challenges, adults with CHD have the potential to also experience positive changes, yet little is known as to what helps cultivate positive adaptation and post-traumatic growth (PTG) within this context. The current study comprised a cross-sectional, anonymous, online study exploring psychosocial measures of traumatic experiences as well as protective factors that mitigate the risks to the mental health of adults with CHD (n=236) during the pandemic. Closed and open-ended questions and a series of standardised psychosocial measures of traumatic experiences, coping mechanisms, emotional regulation and PTG were used. Findings suggest the CHD population are at increased risk of PTSD which may be exacerbated by the COVID-19 pandemic. However, positive adaptation may promote post traumatic growth. In particular, emotional regulation is associated with post-traumatic growth. We recommend a growth-focused, psychologically and trauma-informed approach to medicine and public health, recognising the importance of supporting mental health and promoting living well with CHD during the COVID-19 pandemic and beyond. These findings are likely generalisable to other lifelong health conditions and shielding populations.

Keywords
Congenital heart disease, patient experience, trauma, COVID-19, post-traumatic growth

Introduction

There is emerging evidence that the growing population of adults living with Congenital Heart Disease (CHD) experience a higher prevalence of mental health difficulties including depression, anxiety, Post Traumatic Stress Disorder (PTSD) and neuro-cognitive issues.[1,2,3] Between one third and one-half of adults with CHD meet diagnostic criteria for mood and/or anxiety disorders.[4] Further, 11 – 21% of adults with CHD suffer from PTSD compared to just 3.5 % in the general population.[1] CHD is the most common birth defect with a worldwide prevalence of approximately 1% comprising a medically heterogeneous population.[5,6] Widely considered a success story of modern medicine, infants diagnosed with CHD today have over a 95% chance of reaching adulthood in comparison to 55 years ago when only 25% survived.[7] However, CHD is not curative and members of this population often endure a lifetime of medical monitoring and interventions with increased exposure to a range of psychosocial stressors that contribute to this increased psychological morbidity.[8]

CHD during the COVID-19 pandemic

The COVID-19 pandemic is intensifying health inequalities with the most vulnerable facing the greatest impact physically, economically and socially[9,10,11] while presenting increased risk to mental health for people with underlying health conditions.[12,13] Half of adults in the UK with an underlying health condition report their wellbeing has been affected by the pandemic and anxiety levels remain substantially higher than in the general population.[14] Studies also suggest a negative mental health impact of quarantine and shielding (in the UK 'clinically

vulnerable' groups were asked to stay at home during the global pandemic, termed 'shielding').[15,16,17]

The COVID-19 pandemic presents additional challenges for the CHD population including an increased risk of serious health complications, the psychological impact of shielding and strict social distancing, changes to medical care provision and social stigma which may further negatively impact mental health. Specifically, one recent study reports disruption to cardiac care, concerns about infection and high levels of psychological distress in the CHD population, across the lifespan, during the pandemic.[18] In the UK, some individuals with complex CHD have been advised to socially shield or maintain vigilant social distancing.[19]

Psychological Risk & Protective Factors & Positive Adaptation

Certain *risk factors* increase vulnerability of developing a psychological disorder following exposure to psychological trauma including feeling helpless, poor social support, an accumulation of adverse events, other life stressors and pre-existing physical and mental health problems.[20,21] Whereas *protective factors* can improve mental health outcomes mitigating the impact of psychological trauma including adequate social support and help seeking[22], being able to control some aspects of what is happening, being able to access appropriate psychological support[8] and underlying 'assumptions' about the benevolence of the world, the meaningfulness of events, and the worthiness of the self.[23]

Further, many people report positive personal change following adverse life events including increased resilience, a more positive perspective, a deeper appreciation of life, closer relationships, increased empathy and personal strength, termed post traumatic growth (PTG).[24,25]

Previous studies indicate that emotional regulation mediates PTG.[26,27] Emotional regulation is the ability to effectively monitor, evaluate and modify our emotions, fundamental to everyday functioning. This includes awareness of emotions, tolerance of unpleasant emotions, being able to identify and label emotions, recognise patterns and manage them in healthy way.[28,29]

Gaining a better understanding of the risk and protective factors that mediate psychological health for this population will better enable healthcare providers to support the CHD population during and beyond the COVID-19 pandemic.

Aims

This study aims to explore the extent of self-reported trauma outcomes among adults living with CHD in the UK during the COVID-19 pandemic and the factors that cultivate PTG with the aim of informing strategies to mitigate trauma and support positive adaptation. It was hypothesised that variables designated as coping mechanisms (including emotional regulation and help seeking) would predict higher PTG whilst higher self-reported trauma and adverse traumatic experiences would predict lower PTG.

Methods

Participants

Participants were eligible to complete the survey if they had a CHD, were aged 18 years old or over and were UK residents. Participants were recruited via social media (Twitter and Facebook) and a charity supporting adults with CHDs', email newsletter and website.

Procedure

The study comprised an anonymous, online questionnaire using Qualtrics asking adults living with CHD about the extent of self-reported trauma and post-traumatic growth outcomes. Further, measures that served as potential 'risk' or 'protective' factors were also included. Participants were also asked a series of questions about the nature of their condition, their experiences during the pandemic and two open ended questions to allow further reflections. Participants were directed to the charity's counselling helpline and resources if they required further support or guidance.

Ethics approval & informed consent

Ethical approval was granted by the School of Psychological Sciences and Health Ethics Committee, University of Strathclyde. The research was carried out in accordance with the Declaration of Helsinki[30] for research involving humans. All participants provided informed consent online via Qualtrics to participate in the study. Informed consent was obtained from participants prior to completing the survey online via Qualtrics, which took place between the 19th of May and the 5th of August 2020. Between March and the 1st of August 2020, in the UK people who had been identified as extremely clinically vulnerable were asked to socially 'shield' by staying at home by the government.

Survey

Participants were first asked to provide their socio-demographic information. Participants were then asked questions relevant to the CHD population to capture recommendations about shielding, their concerns about COVID-19 virus and any changes to usual specialist CHD medical care resulting from the current pandemic. Two

open-ended questions (as detailed below) were used at the end of the survey to offer participants the opportunity to provide more information. The survey comprised the following standardized measures:

PTSD Checklist (Civilian Version)[31]: PTSD symptoms were measured using this scale, a 17-item self-report of re-experiencing, avoidance, and hyperarousal symptoms related to the experience of a traumatic event. Items measure problems over the past month using a 5-point Likert-type scale. Prior studies demonstrate good internal stability, test-retest reliability, convergent validity, and temporal stability.[32]

World Assumptions Scale (WAS)[23]: The WAS comprises 22 items measuring fundamental assumptions about the world using a 6-point Likert scale. It yields 4 Subscales: controllability of events, comprehensibility and predictability of people, trustworthiness and goodness of people, and safety and vulnerability. A total score is generated by the summation of all items and the mean of this total was used in the analysis. Previous studies suggest that the WAS has adequate psychometric properties for use in both clinical and research settings.[33]

Adverse Traumatic Experiences Scale – Medical Adversity History Subscale (ATES)[34,35]: This scale was developed to measure a range of potentially traumatic prior experiences. Respondents report on prior adverse events of maltreatment, life-threatening situations, and sudden deaths of close ones which are summed to create an adversity score (range: 0–19). It is based on a synthesis of items that are common to other measures including the ACES, Trauma History Questionnaire, Life Events Checklist for the DSM-5, and Brief Trauma Questionnaire. It includes items about childhood adverse experiences, child maltreatment, life-threatening situations, sudden deaths of close ones, and personal health complications. For the purpose of this study the ATES medical adversity history subscale was included.

Post Traumatic Growth Inventory Subscales Personal Strength and Appreciation (PTGI)[36]: This scale consists of 21 items scored on a 6-point Likert scale. In previous studies, scores on the PTGI have been shown to be reliable when used with participants who identified with having a chronic illness (e.g., $\alpha = .79$).[3] The scale comprises 5 subscales; appreciation, relating to others, new possibilities, personal strength and spiritual enhancement and for the purposes of this study personal strength and appreciation subscales were included.

Regulation of Emotions Questionnaire (REQ)[38]: The REQ is a 20-item scale designed to measure emotional regulation, according to the rater's use of various coping strategies. Strategies are divided between those utilising 'internal' or cognitive resources (e.g., 'I put the situation into perspective') and those utilising 'external' environmental resources and interactions (e.g., 'I concentrate on a pleasant activity'); and between strategies deemed 'functional' (processing negative emotion and/or promoting wellbeing, see previous examples) versus 'dysfunctional' (internally amplifying or suppressing negative emotion e.g., 'I dwell on my thoughts and feelings', 'I keep the feeling locked inside', or externally displacing negative emotion, e.g., 'I bully other people'). The REQ therefore has 4 subscales; internal dysfunctional, internal functional, external dysfunctional and external functional. Respondents answer each item on a 5-point Likert-type scale ranging from 1 ('not at all') to 5 ('always'). The REQ is a valid and reliable self-report questionnaire (Cronbach's alpha = .72, .76, .76 and .66 for internal dysfunctional, internal functional, external dysfunctional and external functional, respectively).[38]

General Help Seeking Questionnaire (GHSQ)[22]: The GHSQ a 10 items scale on a 7- point Likert scale (1 = extremely unlikely, 7 = extremely likely). The GHSQ evaluates the intent to seek help for suicidal problems and for general emotional problems. (Cronbach's alpha = .70, test-retest reliability = .86). The measure has been found to be related to the search for current help during the last month and to predict future intention of seeking help.[39]

Free Text Responses: The following two open-ended questions were used to offer participants the opportunity to provide more information.

- Please detail any more thoughts about the impact of COVID-19 on your mental health and wellbeing.
- How do you feel about the way the media have portrayed the increased risk to people with 'underlying health conditions'?

Statistical Methods

Data exploration was first conducted, observing trends in demographic and descriptive statistics. Multiple linear regression was then conducted using PTGI strength and appreciation subscales as dependent variables, chosen to best represent outcomes in the face of personal and public health challenges such as the COVID-19 pandemic. WAS controllability of events and safety and vulnerability subscales, REQ functional subscales and GHSQ were chosen as coping mechanism independent variables, predicted to influence increased PTG (personal strength and appreciation). ATES medical adversity history subscale and REQ dysfunctional subscales were included as independent variables predicted to have a negative effect on the development of PTG in the face of health adversities. Assumption testing was conducted, excluding WAS safety and vulnerability variables from both regression analyses and GHSQ from the PTG appreciation analysis due to lack of linearity. Pearson's

Table 1. Sociodemographic Characteristics of Participants (N = 236)

Sample Characteristics	*n*	% M	SD
Gender			
Male	54	22.9%	
Female	178	75.4%	
Self-described	3	1.3%	
Education			
University	127	53.8%	
College	71	30.1%	
High School	29	12.3%	
Other	9	3.8%	
Age		42.90	12.26
Country of Residence			
N. Ireland	2	0.8%	
Wales	26	11%	
Scotland	20	.5%	
England	188	79.7%	

Correlations and Multiple Linear Regressions were then performed.

On completing multiple linear regression analysis, a logistical regression was conducted to determine whether independent variables which significantly predicted post-traumatic growth could also predict reduced clinical symptoms of trauma, as interpreted through the likelihood of meeting PTSD-checklist diagnostic threshold scores. Thresholds were derived from DSM IV symptom criteria, with positive diagnosis designated by scores of 3-5 (moderately or above) on at least 1 "B" item (questions 1-5), at least 3 "C" items (questions 6-12) and at least 2 "D" items (questions 13-17).[40] Statistical analysis was conducted in RStudio software for Windows, Version 1.3.1093 © 2009-2020 RStudio, PBC.

Content Analysis

For responses to the two open-ended questions, content analysis of participants' comments was undertaken.[41,42] Initial descriptive codes were applied to participants' written responses. Subsequent text was compared to previously coded text and either allocated an existing code or provided a new one, thus grouping responses by similarity.[43] Category development was guided by established studies.[44] Both coders (LM and CM) initially analysed the data separately, reviewing the codes together, enabling both category refinement and research rigour. The researchers (LM & CM) returned to the data several times during the analytical process to ensure that the results showed a strong connection to the analysed data. The categories of meaning (key categories) represented the highest level of abstraction for the reporting of the results. In the final phase, coded data were treated as variables for analysis conducted using descriptive statistics (frequency counts and percentages) in Microsoft Excel.

Results

In total, 236 participants completed the online survey. The average age of participants was 43 years old (S.D. 12) ranging from 21 to 77 years old who were predominantly female (178, 75%), see Table 1. In total, 221 participants reported the primary nature of their CHD, see Table 2. 90 (38%) of participants had been medically advised to shield while 130 (55%) were shielding. 219 (93%) of participants were under the care of specialist congenital cardiology service.

Participants were asked a series of questions regarding their concerns about COVID-19, as depicted in Table 3. Over half of participants (55%) reported that they had experienced changes to their usual cardiac care due to the current pandemic. Further, 86% of participants reported the pandemic had made them more aware of their CHD while 68% reported feeling that their CHD made the current COVID-19 pandemic more difficult for them. 57% reported feeling that living with CHD helped them deal with the pandemic.

Further, 71/236 (30%) of participants met the cut-off for screening measure for PTSD. The means for measures included in analysis are depicted in Table 4.

PTGI Personal Strength

Following assumption testing, Pearson's correlations were conducted between PTGI personal strength and the 4

Table 2. Congenital Cardiac Condition (N = 221)

Congenital Cardiac Condition	Frequency (%)
Tetralogy of Fallot (ToF)	48 (22%)
Transposition of the Great Arteries (TGA)	35 (16%)
Coarctation of the Aorta	20 (9%)
Pulmonary Atresia	17 (7.6%)
Atrial Septal Defect (ASD)	17 (7.6%)
Aortic Valve Stenosis	16 (7.2%)
Ventral Septal Defect (VSD)	9 (4%)
Pulmonary Stenosis	9 (4%)
Ebstein's Anomaly	8 (3.6%)
Atrioventricular Septal Defect (AVSD)	7 (3%)
Tricuspid Atresia	6 (2.7%)
Bicuspid Aortic Valve	6 (2.7%)
Double Outlet Right Ventricle (DORV)	5 (2.2%)
Eisenmenger Syndrome	4 (1.8%
Cardiomyopathy	2 (0.6%)
Shone's Syndrome	2 (0.6%)
Congenital Heart Block	2 (0.6%)
Single Ventricle	2 (0.6%)
Mitral Valve Prolapse	1 (0.3%)
Hypoplastic Left Heart Syndrome	1 (0.3%)
Other	4 (1.2%)

Table 3. Participants' concerns about the COVID-19 virus

Question	Very worried	Somewhat worried	A little worried	Not worried
How much are you worried that you will become seriously ill because of the COVID-19 virus?	51%	28%	18%	3%
How much are you worried that you will be unable to access specialist congenital cardiac medical care if you became infected with COVID-19?	39%	25%	20%	16%
How worried are you about becoming infected with COVID-19 virus?	31%	38%	26%	5%
How much are you worried that you will be unable to access non COVID-19 medical care if required during the pandemic?	19%	33%	27%	21%
How much are you worried that you will become infected by your child/children if they attend school?	17%	14%	12%	57%
How much are you worried you will be unable to get necessary medications	11%	17%	31%	41%
How much are you worried that you will lose your job?	11%	11%	17%	61%
How much are you worried that you will be less financially stable?	15%	20%	27%	38%
How much are you worried that you will be unable to care for your child/children?	9%	14%	17%	60%
How much are you worried that you will be unable to get important necessities?	7%	15%	28%	50%

REQ Subscales, ATES medical adversity history subscale, WAS controllability of events subscale and GHSQ scores. PTGI personal strength showed moderate significant correlation with REQ functional subscales and a small significant correlation with WAS controllability of events. Further details are provided in Table 4.

Multiple linear regression analysis of the same independent variables was found to explain a significant amount of variance in PTGI personal strength scores ($F(7, 227) = 13.07$, $p < .001$, $R^2 = .29$, $R^2_{Adjusted} = .27$). The two REQ functional subscales significantly contributed to the model, whilst other independent variables did not (see Table 4).

Table 4. Means, standard deviations, and correlations with confidence intervals PTGI strength

Variable	*M*	*SD*	1	2	3	4	5	6	7
1. PTGI strength subscale	10.36	5.14							
2. ERQ internal functional subscale	1.79	0.66	.45** [.34, .55]						
3. ERQ external functional subscale	1.74	0.78	.43** [.32, .53]	.54** [.44, .62]					
4. ERQ internal dysfunctional subscale	1.41	0.80	-.17** [-.29, -.04]	-.18** [-.30, -.06]	-.28** [-.39, -.16]				
5. ERQ external dysfunctional subscale	0.50	0.42	-.17** [-.29, -.05]	-.23** [-.35, -.10]	-.17* [-.29, -.04]	.46** [.35, .55]			
6. ATES personal health subscale	2.10	1.09	.08 [-.04, .21]	-.04 [-.17, .09]	-.02 [-.15, .10]	-.03 [-.15, .10]	.02 [-.11, .15]		
7. WAQ controllability of events subscale	3.36	0.91	.22** [.09, .34]	.24** [.11, .35]	.17** [.04, .29]	-.39** [-.49, -.28]	-.14* [-.26, -.01]	.01 [-.12, .14]	
8. SHQ	3.85	1.14	.11 [-.02, .23]	.01 [-.12, .14]	.06 [-.07, .19]	.06 [-.06, .19]	-.05 [-.18, .08]	-.03 [-.16, .10]	.05 [-.08, .17]

Note. M and SD are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. The confidence interval is a plausible range of population correlations that could have caused the sample correlation (Cumming, 2014). * indicates $p < .05$. ** indicates $p < .01$.

PTGI Appreciation

Pearson's correlations were conducted between PTGI appreciation and the 4 REQ subscales, ATES medical adversity history subscale, WAS controllability of events subscale and GHSQ scores. PTGI appreciation showed moderate significant correlation with REQ functional subscales and a small significant correlation with REQ dysfunctional subscales. PTGI appreciation showed a small correlation with WAS controllability of events subscale and ATES medical adversity history subscale, as shown in Table 5, however this finding was non-significant ($p = 0.075$ and 0.056 respectively). Multiple linear regression analysis indicated that the selected model predicted a significant percentage of variance ($F(6, 229) = 11.43$, $p < .001$, $R^2 = .23$, $R^2_{Adjusted} = .21$). As with PTGI strength, REQ functional subscales

Table 5. Means, standard deviations, and correlations with confidence intervals PGTI appreciation

Variable	*M*	*SD*	1	2	3	4	5	6
1. PTGI appreciation subscale	8.64	3.76						
2. ERQ internal functional subscale	1.79	0.66	.40** [.29, .50]					
3. ERQ external functional subscale	1.74	0.78	.39** [.28, .49]	.54** [.44, .62]				
4. ERQ internal dysfunctional subscale	1.41	0.80	-.19** [-.31, -.07]	-.18** [-.30, -.06]	-.28** [-.39, -.16]			
5. ERQ external dysfunctional subscale	0.50	0.42	-.16* [-.28, -.04]	-.23** [-.35, -.10]	-.17* [-.29, -.04]	.46** [.35, .55]		
6. ATES personal health subscale	2.10	1.09	.12 [-.00, .25]	-.04 [-.17, .09]	-.02 [-.15, .10]	-.03 [-.15, .10]	.02 [-.11, .15]	
7. WAQ controllability of events subscale	3.36	0.91	.12 [-.01, .24]	.24** [.11, .35]	.17** [.04, .29]	-.39** [-.49, -.28]	-.14* [-.26, -.01]	.01 [-.12, .14]

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. The confidence interval is a plausible range of population correlations that could have caused the sample correlation (Cumming, 2014). * indicates $p < .05$. ** indicates $p < .01$.

significantly contributed to the model, however in this case ATES medical adversity history subscale severity was also significant.

PTSD-Checklist Scores

As REQ functional subscales were significant in predictive models for both PTGI personal strength and appreciation scores, these same variables were used to create a logistical regression model to predict the likelihood of passing threshold criteria for DSM-IV derived diagnostic indicators for PTSD-Checklist scores. REQ internal functional subscale and external functional subscale were non-significant in predicting PTSD-Checklist diagnostic thresholds. For the overall model, the unstandardised Beta weight of the Constant was $B = (-.09)$, $SE = .43$, $Wald = -.23$, $p = .822$. The unstandardised Beta weight of REQ internal functional subscale was $B = (-.01)$, $SE = .26$, $Wald = -.02$, $p = .977$. Unstandardized Beta weight for the REQ external functional subscale was $B = (-.44)$, $SE = .22$, $Wald = -1.95$, $p = .0.051$. As the REQ external functional subscale approached significance, estimated odds ratios are reported: favoring a decrease of 36% in likelihood of PTSD symptoms for every one-unit increase in REQ external functional score; *Exp (B)* = .64, 95% CI (.41, 1.00).

Free Text Responses

Question 1: Please detail any more thoughts about the impact of COVID-19 on your mental health and wellbeing here.

One hundred and forty-four participants provided 144 responses to Question 1. The majority of participants referred to factors which reflected their anxieties and CHD specific concerns about the COVID-19 pandemic.

Overall, responses generated a total of 14 associated codes (sub-codes), resulting in 7 categories of meaning (see Table 6). Categories of meaning (key codes) were: (1) Anxieties (32%) (e.g., 'Potential to lose my job and life') (2) CHD specific concerns (23%) (e.g., 'Made me more aware of my condition and the measures I should take to mitigate risk

Table 6. Question 1, Categories of meaning and associated codes

Categories of meaning (key categories)	No (%) comments per category	Associated codes (sub-codes)	Example Quote
Anxieties (46, 32%)	17 (12%)	Concerns about the future	Trying to stay positive but still worried how the future (12-24 months) will look and how that will impact my life as currently feel am in limbo
	16 (11%)	Increased distress, anxiety and low mood	My mental health feels worse now and I feel we have all been forgotten about
	13 (9%)	Fear of contamination	I'm worried I will have a bad reaction to it and this will impact on my young children
CHD specific concerns (33, 23%)	12 (8%)	Lack of specialist guidance and support	It's all very distressing and I wish GP or cardiologist had been in touch with specific advice
	6 (4%)	Concerns about medical care	Delaying my surgery has caused me distress
	10 (7%)	Increased awareness of CHD	Just feel for the first time in my life that I have had to admit that I have a congenital heart and lung condition, I find it easy living a lie as I find people treat me differently when they find out about me
	3(2%)	Concerns about understanding from work	Stress caused by work situation - would be classed as a frontline worker so risk relatively high. Inconsistency by employer's response.
	2 (1%)	Using patient expertise to cope	I feel that the depth of my awareness re my personal health condition has led me to make what I consider to be, the best decisions regarding safeguarding both my health and that of my husband
Social isolation	14 (10%)		It's shut me off from my usual support networks which in turn has made me feel alone.
Frustration with media and government handling	13 (9%)		I am angry with Boris Johnson and his caviler attitude to the disease.
Opportunity for reflection & recuperation	10 (7%)		Made me realise even more how important those I have in my life are to me.
Safety seeking	5 (3%)		It's been tough at times but felt safe in the house
Stiff upper lip	5 (3%)		Little impact, seeing this as one more of life's trials which will be overcome.
Miscellaneous	18 (14%)		Been ok but need normality now

and stay safe'), (3) Social isolation (10%) (e.g., 'The virus has caused me to become socially isolated as I am off work and cannot work from home.'), (4) Frustrations with the media and government handling (9%) (e.g. 'I feel this situation has been badly managed by the media and I think everyone with a severe condition should have received personal guidance on what to do and how to stay safe'), (5) Opportunity for reflection and recuperation (7%) (e.g., For the most part it's been better as I've been able to take a breather and focus on me'), (6) Safety seeking (3%) (e.g., 'When case numbers were high, I just wanted all my family to stay home and be safe in our little bubble. My husband took time off work on sick leave to alleviate my anxieties.'), and (7) Stiff upper lip (3%) (e.g., 'No affect whatsoever it is what it is and just get on the best I can'). 18 (14%) comments were categorised miscellaneous as they were too broad or fragmented to categorise.

Question 2: How do you feel about the way the media have portrayed the increased risk to people with 'underlying health conditions?

211 Participants provided 221 responses to Question 2. The majority of participants referred to factors which reflected a sense the media has been unfair to people with

Table 7. Questions 2, Categories of meaning and associated codes

Categories of meaning (key categories)	No (%) comments per category	Associated codes (sub-codes)	Example Quote
Unfair to people with UHCs (174, 79%)	73 (33%)	Scaremongering	It's been somewhat scaremongering
	43 (20%)	Unrepresentative	They frequently refer to the group as over 70s, and I think it skews public view of who is at increased risk. It's unhelpful.
	27 (12%)	Contradictory and confusing	They've sent mixed messages
	17 (8%)	Scapegoating	I feel that the implication is that people with underlying health conditions are fragile, less valuable or a burden.
	14 (6%)	Insensitive	I feel they have the need to frighten people with health conditions without actually explaining what to do or what they mean. I feel there has always been very mixed signals during this period
Balanced/Fair	29 (13%)		Ok, its hard for them to be specific as there are so many different conditions
Avoidance	7 (3%)		Haven't been watching. I have avoided the media as much as I can
Miscellaneous	11 (5%)		I don't know enough about this to make a solid comment.

underlying health conditions (UHCs). Overall, responses generated a total of 7 associated codes (sub-codes), resulting in 3 categories of meaning (see Table 7). Categories of meaning (key codes) were: (1) Unfair to people with UHCs (79%) (e.g., 'I felt like people with underlying health conditions were assumed to be frail or have a lower quality of life, and like it wasn't as bad if we died of covid compared to the rest of the population'), (2) Balanced and Fair (13%) (e.g., 'We need to know these risks') and (3) Avoidance (3%) (e.g., It has scared me so much that I stopped reading it'). Eight comments (5%) were categorised as miscellaneous as they were too broad or fragmented to categorise.

Key Findings

- Emotional regulation is associated with post-traumatic growth (appreciation and personal strength sub-scales) for this population.
- Exploratory statistics suggest the CHD population are at increased risk of PTSD which may be exacerbated by the COVID-19 pandemic. Specifically, 30% of participants met the cut-off for the screening measure for PTSDRegulation of emotion does not predict PTSD scores for this population.
- Participants detail a variety of anxieties and concerns about the impact of COVID-19 in relation to their CHD and beyond.

Discussion

Despite narratives depicting the COVID-19 pandemic as 'The Great Equaliser' it is becoming apparent that the virus is increasing health inequalities.[9,10,11] Adults living with CHD already faced increased vulnerability to mental health problems pre COVID-19[4] due to exposure to a number of unique psychosocial stressors and cardiac medical events. Such events often consist of unique traumatizing characteristics including the abruptness of the event, the risk of death, loss of control and helplessness and exposure to potentially traumatic medical procedures such as pacemaker implant, ICD (implantable cardioverter-defibrillator) shock and cardiac surgery. Together, this can result in what has been termed Cardiac Induced PTSD (CI-PTSD).[45] Further, the relationship between cardiac health and trauma is bidirectional with studies reporting PTSD as a risk factor for heart disease.[46] The COVID-19 pandemic potentially adds to the burden of living with CHD with studies indicating increased risk to mental health for people with underlying health conditions.[18,47,13]

In the current study, almost a third of the participants (30%) met the cut-off for the screening measure for PTSD, this compares with 13.5% in the general population.[48] This is consistent with previous studies which highlight an increased prevalence of PTSD in the CHD population[1] which may be exacerbated by the current pandemic.

Feeling powerless, vulnerable and socially isolated whilst facing additional psychosocial stressors are risk factors which may contribute to the increased prevalence of PTSD reported in the CHD population.[8] Findings from this study indicate the pandemic may be further exacerbating these factors with over half of participants reporting changes to their usual cardiac care during the pandemic and most reporting that they feel worried about becoming infected and seriously ill with the virus. The majority of participants also reported concerns about accessing medical care in event of infection and being able to access 'non-COVID-19' medical care during the pandemic. Together this may increase feelings of uncertainty and powerlessness. This is consistent with a previous study reporting disruption to cardiac care, concerns about infection and high levels of psychological distress in CHD population during the pandemic.[18] Concerns about being able to access specialist care were already apparent prior to the COVID-19 pandemic because service provision has often not evolved in time to meet the needs of the growing population of adults with CHD. As such it can be inconsistent and difficult to access especially during a medical emergency.[49] Additional concerns about being able to access care during the pandemic will potentially add to the burden of living with this condition. Further, a high number of participants reported feeling more aware of their CHD (86%) and that previous health difficulties made the pandemic more difficult for them (68%) potentially heightening feelings of vulnerability. Categories of meaning and key codes derived from responses to the free text questions further highlighted concerns about a lack of specialist advice and support and increased feelings of vulnerability.

Psychosocial stressors have also increased during the pandemic for this population. Concerns about the impact of the pandemic on finances and employment, family and parenting were reported. This is concerning since a range of studies, pre COVID-19, have demonstrated a negative impact of CHD on both educational attainment and employment status.[5o] While compared to healthy adults even among the healthiest adults with CHD there are significant decrements in life expectancy, employment, and lifetime earnings.[51] Categories of meaning and key codes derived from responses to the responses to the free text questions further emphasised concerns about the future, contamination and increased feelings of distress (anxiety and low mood) and social isolation. Together these findings indicate improved specialist advice and support from healthcare providers is warranted to empower and support members of this population. Keeping patients informed about how and when to access healthcare provision, both cardiac and in the event of becoming infected with COVID-19, could help to alleviate concerns. Further, providing regular, up-to-date recommendations about COVID-19 would also help to empower this population and alleviate concerns.

Negative media portrayals may increase psychosocial stress for the CHD population. Categories of meaning and key codes derived in response to the second free text question regarding media coverage revealed that participants reported feeling this had been unfair to people with UHCs which was described as scaremongering, unrepresentative, contradictory and insensitive while scapegoating people with UHCs. It is essential that media and public health messages are more sensitive to people with UHCs and careful about potentially fueling discrimination and leaving people with underlying health conditions feeling further marginalised and dispensable.

Exploration of our findings reveal the importance of emotional regulation in predicting PTG, subscales strength and appreciation, among the CHD population during the pandemic. These findings suggest the importance of fostering healthy emotional regulation in promoting PTG among adults with CHD. These findings are consistent with previous studies linking emotional regulation and PTG.[26,27] Pro-actively fostering emotional regulation could be incorporated into treatment provision for CHD to support mental health across the lifespan.

Self-management may also be considered positive adaptation to living with CHD.[52] Interestingly 38% of participants had been medically advised to shield while 55% were shielding indicating some participants had taken their health into their own hands. Further 57% of participants reported feeling that living with CHD helped them deal with the pandemic.

Interestingly PTG (appreciation and strength sub-scales) does not predict PTSD scores for this population. This is important to bear in mind since positive adaptation may mask psychological distress in this population.[8]

Limitations

Some limitations of the current study should be noted. The PTSD measure employed is a non-diagnostic, self-report screening measure. Further, more females than males completed the online survey. Conclusions from the study are limited because it was cross-sectional and a follow up longitudinal study is recommended.

Conclusion

In conclusion, the findings from this study indicate a high prevalence of PTSD within the CHD population likely resulting from increased exposure to a combination of psychosocial stressors exacerbated by the COVID-19 pandemic. The mental health needs of the CHD population are frequently under-recognised and under-treated.[2] Findings also suggest that measures could be taken to pro-actively promote positive adaptation for people with CHD. Specifically, emotional regulation seems to promote PTG which could be facilitated across the life journey through psychoeducation relating to self-regulation techniques and/or delivery of psychological therapy. As previously suggested[8] this could be addressed as part of a psychologically informed approach to healthcare provision for this population specifically via inclusion of psychologists as part of the core medical team and timely access to psychological support when needed.

Together, we recommend a growth-focused, psychologically and trauma-informed approach to medicine and public health, recognising the importance of supporting mental health and living well with CHD during pandemic and beyond.[8]

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Conflicts of interest/competing interests

The authors have no relevant financial or non-financial interests to disclose.

Authors' Contribution Statements

All authors contributed to the study conception and design. Material preparation and data collection were performed by all authors. Data analysis was performed by Calum Calderwood, Liza Morton, Claire Murphy, Jacek Kolacz and Evan Nix. The first draft of the manuscript was written by Liza Morton. Liza Morton, Nicola Cogan, Jacek Kolacz, Claire Murphy and Calum Calderwood contributed to the final manuscript, which all authors read and approved.

Data Availability Statement

The study reported in this article was not formally preregistered. Neither the data nor the materials have been made available on a permanent third-party archive; requests for the data or materials can be sent via email to the lead author at Liza.Morton@gcu.ac.uk.

References

1. Deng LX, Khan AM, Drajpuch D *et al.* Prevalence and correlates of post-traumatic stress disorder in adults with congenital heart disease. *American Journal of Cardiology*, 2016;1117(5): 853–857.
2. Kovacs AH, Saidi AS, Kuhl EA *et al.* Depression and anxiety in adult congenital heart disease: Predicots and prevalence. *International Journal of Cardiology,* 2009;137: 158–164
3. Ringle ML, Wernovsky G. Functional, quality of life, and neurodevelopmental outcomes after congenital cardiac surgery. *Seminars in Perinatology,* 2016; 40(8): 556–570.
4. Kovacs AH, Bellinger DC. Neurocognitive and psychosocial outcomes in adult congenital heart disease: a lifespan approach. *Heart*; 2020. doi: 10.1136/heartjnl-2016-310862. [Epub ahead of print]
5. Spector LG, Menk JS, Knight JH, McCracken C, Thomas AS, Vinocur JM, Oster ME, St Louis JD, Moller JH, Kochilas L. Trends in Long-Term Mortality After Congenital Heart Surgery*, Journal of the American College of Cardiology*, 2018;P 2434-2446, V 71, N 21, doi:10.1016/j.jacc.2018.03.491
6. Ntiloudi D, Gatzoulis MA, Arvanitaki A, Karvounis H., Giannakoulas G. Adult congenital heart disease: Looking back, moving forward, *International Journal of Cardiology Congenital Heart Disease*, 2021;Volume 2, 100076, ISSN 2666-6685, https://doi.org/10.1016/j.ijcchd.2020.100076.
7. Ooues, G, Clift P, Bowater S *et al.*. Patient experience within the adult congenital heart disease outreach network: a questionnaire-based study. *J Congenit Heart Dis,* 2018;2, 7. https://doi.org/10.1186/s40949-018-0020-3
8. Morton, L. Using psychologically informed care to improve mental health & wellbeing for people living with a heart condition from birth: A statement paper, *Journal of Health Psychology*, 2020;25, 2, doi.org/10.1177/1359105319826354
9. Cowden RG, Davis EB, Counted V, Chen Y, Rueger SY, VanderWeele TJ, Lemke AW, Glowiak KJ, Worthington EL. Suffering, Mental Health, and Psychological Well-being During the COVID-19 Pandemic: A Longitudinal Study of U.S. Adults with Chronic Health Conditions, *Wellbeing, Space and Society*, 2021;100048,ISSN 2666-5581, https://doi.org/10.1016/j.wss.2021.100048.
10. Holmes EA, O'Connor, RC, Perry VH, Tracey I, Wessely S, Arseneault L, Ballard C, Christensen H, Silver RC, Everall I, Ford T, John A, Kabir T, King KL, Madan I, Michie S, Przybylski AK, Shafran R, Sweeney A, Worthman CM, Yardley L, Cowan K, Cope CL, Hotopf M, Bullmore E. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *The Lancet. Psychiatry*, 2020.

11. Vieira CM, Franco OH, Restrepo CG, Abel T. COVID-19: The forgotten priorities of the pandemic. *Maturitas*, 2020;136, 38 - 41.
12. Kwong A, Pearson R, Adams M, Northstone K, Tilling K, Smith D, Timpson N. Mental health before and during the COVID-19 pandemic in two longitudinal UK population cohorts. *The British Journal of Psychiatry,* 2021;18(6), 334-343. doi:10.1192/bjp.2020.242
13. Umucu E, Lee B. Examining the impact of COVID-19 on stress and coping strategies in individuals with disabilities and chronic conditions. *Rehabilitation psychology,* 2020.
14. Office for National Statistics (ONS): Coronavirus and the social impacts on Great Britain, September 2020 & Personal and economic well-being in Great Britain: September 2020
15. Melo MC, Soares DD. Impact of social distancing on mental health during the COVID-19 pandemic: An urgent discussion. *The International journal of social psychiatry*, 2020;20764020927047 .
16. Jacobson NC, Lekkas D, Price G, Heinz MV, Song M, O'Malley AJ, Barr PJ. Flattening the mental health curve: COVID-19 stay-at-home orders result in alterations in mental health search behavior in the United States. 2020. https://psyarxiv.com/24v5b/
17. Williams SN, Armitage CJ, Tampe T, Dienes K. (2020). Public perceptions and experiences of social distancing and social isolation during the COVID-19 pandemic: A UK-based focus group study. *medRxiv,* 2020. https://www.medrxiv.org/content/10.1101/2020.04.10.20061267v1
18. Cousino MK, Pasquali SK, Romano JC, Norris MD, Yu S, Reichle G, Lowery R, Viers S, Schumacher KR. Impact of the COVID-19 pandemic on CHD care and emotional wellbeing. *Cardiol Young,* 2021;31(5):822-828. doi: 10.1017/S1047951120004758. Epub 2020 Dec 14. PMID: 33308334; PMCID: PMC7783141.
19. Radke RM, Frenzel T, Baumgartner H, Diller G. Adult congenital heart disease and the COVID-19 pandemic. *Heart,* 2020.
20. Brewin CR, Andrews B, Valentine JD. Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology,* 2000;68(5), 748–766. https://doi.org/10.1037/0022-006X.68.5.748
21. Zeligman M, Bialo JA, Brack JL, Kearney MA. Loneliness as Moderator Between Trauma and Posttraumatic Growth. *Journal of Counseling & Development*, 2017;95: 435-444. https://doi.org/10.1002/jcad.12158
22. Wilson CJ, Deane FP, Ciarrochi J, Rickwood D. Measuring Help-Seeking Intentions: Properties of the General Help-Seeking Questionnaire. *Canadian Journal of Counselling*, 2005;39(1), 15-28.
23. Janoff-Bulman R. Assumptive worlds and the stress of traumatic events: Applications of the schema construct. *Social Cognition,* 1989*;7*(2), 113 136. https://doi.org/10.1521/soco.1989.7.2.113
24. Stellar JE, Cohen A, Oveis C *et al.* Affective and physiological responses to the suffering of others: Compassion and vagal activity. *Journal of Personality and Social Psychology,* 2015;108(4):572–585.
25. Staub E, Vollhardt J. Altruism born of suffering: The roots of caring and helping after victimization and other trauma. *American Journal of Orthopsychiatry,* 2008; 78: 267–280.
26. Orejuela-Dávila, AI, Levens SM, Sagui-Henson SJ, Tedeschi RG, Sheppes G. The relation between emotion regulation choice and posttraumatic growth, *Cognition and Emotion*, 2019;22, 8
27. Kira IA, Arıcı Özcan N, Shuwiekh H, Kucharska J, Al-Huwailah AH, Kanaan A. The compelling dynamics of "will to exist, live, and survive" on effecting posttraumatic growth upon exposure to adversities: Is it mediated, in part, by emotional regulation, resilience, and spirituality? *Traumatology,* 2020;26(4), 405–419. https://doi.org/10.1037/trm0000263
28. Gross J. Emotion Regulation: Current Status and Future Prospects. *Psychological Inquiry*, 2015;26: 1–26, 201.
29. Torre JB, Lieberman MD. "Putting feelings into words: Affect labeling as implicit emotion regulation." *Emotion Review,* 2018*;* 10.2: 116-124.
30. World Medical Association. WMA Declaration of Helsinki – ethical principles for medical research involving human subjects; 2013. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
31. Weathers, FW, Litz BT, Keane TM, Palmieri PA, Marx BP. & Schnurr PP. *The PTSD Checklist for DSM-5 (PCL-5)*, 2013.
32. Wilkins KC, Lang AJ, Norman SB. Synthesis of the psychometric properties of the PTSD checklist (PCL) military, civilian, specific versions. *Depres Anxiety.* 2011;28:596–606. doi: 10.1002/da.20837.
33. Elklit A, Shevlin M, Solomon Z, Dekel R. Factor structure and concurrent validity of the world assumptions scale. J. Traum. Stress, 2007;20: 291-301. https://doi.org/10.1002/jts.20203
34. Dale LP, Davidson C, Kolacz J. Adverse Traumatic Experiences Scale, 2020.
35. Kolacz J, Dale LP, Nix EJ, Roath OK, Lewis GF, Porges SW. Adversity History Predicts Self-Reported Autonomic Reactivity and Mental Health in US Residents During the COVID-19 Pandemic[. *Frontiers in Psychiatry,* 2020; 11(1119). https://doi.org/10.3389/fpsyt.2020.577728
36. Tedeschi, Calhun. Post Traumatic Growth Inventory, 1996.
37. Purc-Stephenson RJ. The Posttraumatic Growth Inventory: Factor structure and invariance among

persons with chronic diseases. *Rehabilitation Psychology*, 2014;59, 10–18. doi:10.1037/a0035353
38. Phillips KF, Power M. A new self-report measure of emotion regulation in adolescents: The Regulation of Emotions Questionnaire. *Clinical Psychology & Psychotherapy*, 2007;14, 145-156. doi:10.1002/cpp.523
39. Olivari C, & Guzmán-González M. Validation of the general help-seeking questionnaire for mental health problems in adolescents. *Revista Chilena de Pediatria*, 2017;*88*(3), 324-331.
40. Blanchard E, Jones-Alexander J, Buckley T, Forneris C. Psychometric properties of the PTSD Checklist (PCL). *Behaviour research and therapy*, 1996;34 8, 669-673.
41. Krippendorff K. *Content analysis: an introduction to its methodology,* Sage, 2018.
42. Kyngäs H, Kääriäinen M, Elo S. *The trustworthiness of content analysis*, 2020.
43. Leech, NL, Onwuegbuzie AJ. An array of qualitative data analysis tools: a call for qualitative data analysis triangulation. *School Psychol Quart*, 2007; 22, pp. 557-584
44. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study, *Nurs Health Sci*, 2013;15, pp. 398-405, 10.1111/nhs.12048
45. Vilchinsky N, Ginzburg K, Fait K, Foa EB. Cardiac-disease-induced PTSD (CDI-PTSD): *A systematic review, Clinical Psychology Review*, 2021;Volume 55, 2017, Pages 92-106, ISSN 0272-7358, https://doi.org/10.1016/j.cpr.2017.04.009.
46. Edmondson D, Kronish IM, Shaffer JA, Falzon L, Burg, MM. Posttraumatic stress disorder and risk for coronary heart disease: A meta-analytic review, *American Heart Journal*, 2013;Volume 166, Issue 5, 806-814, ISSN 0002-8703, https://doi.org/10.1016/j.ahj.2013.07.031.
47. Kwong A, Pearson R, Adams M, Northstone K, Tilling, K., Smith D, Timpson N. Mental health before and during the COVID-19 pandemic in two longitudinal UK population cohorts. *The British Journal of Psychiatry,* 2021;218(6), 334-343. doi:10.1192/bjp.2020.242
48. Ruggiero KJ, Ben KD, Scotti JR *et al.* Psychometric Properties of the PTSD Checklist—Civilian Version. *J Trauma Stress* 2003;16, 495–502. https://doi.org/10.1023/A:1025714729117
49. Wray J, Friglola A., Bull C. Loss to specialist follow-up in congenital heart disease; out of sight, out of mind. *Heart*, 2012;99 (7): 485–490.
50. Kamphuis M, Vogels T, Ottenkamp J, van der Wall EE, Verloove-Vanhorick, SP, Vliegen HW. Employment in adults with congenital heart disease. *Arch Pediatr Adolesc Med*, 2002;156(11):1143. https://doi.org/10.1001/archpedi.156.11.1143
51. Gong CL, Zhao, H, Wei, Y *et al.* (Lifetime Burden of Adult Congenital Heart Disease in the USA Using a Microsimulation Model. *Pediatr Cardiol,* 2020. https://doi.org/10.1007/s00246-020-02409-9
52. Hays LH, McSweeney JC, Mitchell A., Bricker C, Green A, Landes RD Self-management Needs of Adults With Congenital Heart Disease, *The Journal of Cardiovascular Nursing*, 2020;35; 6, E33-E43. doi: 10.1097/JCN.0000000000000701