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

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Conflicts of interest/competing interests

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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@glasgow.ac.uk.

ABSTRACT

Introduction: 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.

Methods: 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 mental health on the mental health for 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 measured.

Results: 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, health adversity is associated with greater appreciation whilst emotional regulation is associated with post-traumatic growth.

Conclusions: 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.

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 (Deng, 2016; Kovacs *et al*, 2009; Ringle and Wernovsky, 2016). Between one third and one-half of adults with CHD meet diagnostic criteria for mood and/or anxiety disorders (Kovacs and Bellinger, 2020). Further 11 - 21% of adults suffer from PTSD compared to just 3.5% in the general population (Deng, 2016). CHD is the most common birth defect with a worldwide prevalence of approximately 1% comprising a medically heterogeneous population (Logan *et al*, 2018; Ntiloudi, *et al* 2021). Widely considered a success story of modern medicine, infants diagnosed with CHD today have over a 95 percent chance of reaching adulthood in comparison to 55 years ago when only 25 percent survived (Ooues, 2018). 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 (Morton, 2020).

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 (Cowden *et al*, 2021; Holmes *et al*, 2020; Vieira *et al*, 2020) while presenting increased risk to mental health for people with underlying health conditions (Kwong *et al*, 2020; Umucu and Lee, 2020). 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 (ONS, 2020). 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’) (Melo, *et al*, 2020; Jacobson *et al*, 2020; Williams, *et al* 2020).

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 during pandemic for the CHD population, concerns about infection and high levels of psychological distress in CHD population, across the lifespan (Cousino *et al*, 2020). In the UK, some individuals with complex CHD have been advised to socially shield or maintain vigilant social distancing (Radke, *et al*, 2020).

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 (Brewin, *et al*, 2000; Zeligman *et al*, 2017). Whereas *protective factors* can improve mental health outcomes mitigating the impact of psychological trauma including adequate social support and help seeking (Wilson *et al*, 2005) being able to control some aspects of what is happening, being able to access appropriate psychological support (Morton, 2020) and underlying ‘assumptions’ about the benevolence of the world, the meaningfulness of events, and the worthiness of the self (Janoff-Bulman, 1989).

Further, many people report positive personal change following adverse life events including increased resilience, more positive perspective, deeper appreciation of life, closer relationships, increased empathy and personal strength, termed Post Traumatic Growth (PTG) (Stellar *et al.*, 2015; Staub and Vollhardt, 2008).

Previous studies indicate that Emotional regulation mediates PTG (Orejuela-Davila *et al*, 2019; Kira *et al*, 2020). 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 (Gross, 2015; Torre and Lieberman, 2018).

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 (detailed below). 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 anonymized. The research was carried out in accordance with the Declaration of Helsinki (World Medical Association, 2013) 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) (Weathers *et al.*, 2013): 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 (Wilkins *et al.*, 2011).

World Assumptions Scale WAS (Janoff-Bulman, 1989): 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 (Elklit *et al.*, 2007).

Adverse Traumatic Experiences Scale (Dale, Davidson and Kolacz, 2020; Kolacz *et al.*, 2020): This Scale was developed to measure a range of potentially-traumatic prior experiences. 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.

Post Traumatic Growth Inventory (Tedeschi and Calhoun, 1996): 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., $\alpha = .79$, Purc-Stephenson, 2014; $\alpha = .93$, Rogan *et al*, 2013).

Emotional Regulation Questionnaire (ERQ, Gross and John, 2003): This scale was used to assess emotion regulation. The ERQ is a valid and reliable self-report questionnaire (Cronbach's alpha = .79 and .73 for reappraisal and suppression scales, respectively) that includes 10 items rated on a Likert scale. The overall score of the tool is the item average, ranging between 1 and 7. A higher score in the reappraisal strategy indicates more frequent use of adaptive emotion regulation and a higher score in the suppression strategy indicates a more frequent use of non-adaptive emotion regulation.

General Help Seeking Questionnaire (GHSQ, Wilson *et al*, 2005)

The GHSQ evaluates the intent to seek help for suicidal problems, and for general emotional problems. The study of the psychometric properties of this questionnaire has shown that the measure of intention to seek help is related to the search for current help during the last month and predicts the future intention of seeking help.

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 here.
- 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 conducted using Posttraumatic Growth Inventory strength and appreciation subscales as dependent variables against influencing ‘coping mechanism’ independent variables (WAQ subscales, ERQ subscales and GHSQ) and ATES personal health subscale severity. Assumption testing was conducted, excluding additional variables from analysis due to lack of linearity. Pearson’s 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) (Blanchard *et al.*, 1996). 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 (Krippendorff, 2018; Kyngäs *et al.*, 2020). 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 (Leech and Onwuegbuzie, 2007). Category development was guided by Vaismoradi *et al.* (2013). 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.

INSERT TABLE 1 HERE

INSERT TABLE 2 HERE

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.

INSERT TABLE 3 HERE

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.

INSERT TABLE 4 HERE

PTGI Strength

Following assumption testing, Pearson's correlations were conducted between PTGI Strength and the 4 ERQ subscales, ATE Personal Health subscale, WAQ Controllability of Events Subscale and GHSQ scores. PTGI Strength showed moderate significant correlation with ERQ Functional subscales and a small significant correlation with WAQ Controllability of Events. Further details are provided in the Table 4.

INSERT TABLE 5 HERE

Multiple linear regression analysis of the same independent variables was found to explain a significant amount of variance in PTGI Strength scores ($F(7, 227) = 13.07, p < .001, R^2 = .29, R^2_{Adjusted} = .27$). The two ERQ Functional subscales significantly contributed to the model, whilst other independent variables did not (see Table 5).

PTGI Appreciation

Pearson's correlations were conducted between PTGI and the 4 ERQ subscales, ATE Personal Health subscale, WAQ Controllability of Events Subscale and GHSQ scores. PTGI Appreciation showed moderate significant correlation with ERQ Functional subscales and a small significant correlation with ERQ dysfunctional subscales. PTGI Appreciation showed small and significant correlation with WAQ Controllability of Events subscale and ATE Personal Health Subscale, as shown in Table 6.

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, ERQ Functional Subscales significantly contributed to the model, however in this case ATES Personal Health Subscale severity was also significant.

PTSD-Checklist Scores

As ERQ Functional Subscales were significant in predictive models for both PTGI 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. ERQ Internal Functional Subscale and External Functional subscale were non-significant. The unstandardised Beta weight of the Constant was $B = (-.09), SE = .43, Wald = -.23, p = .822$. The unstandardised Beta weights of ERQ Internal and External Functional Subscales was $B = (-.01), SE = .26, Wald = -.02, p = .977$ and $B = (-.44), SE = .22, Wald = -1.95, p = .051$ respectively. The estimated odds ratio favoured a decrease of 36% in likelihood of PTSD symptoms for every one-unit increase in ERQ External Functional score; $Exp(B) = .64, 95\% CI (.41, 1.00)$.

INSERT TABLE 6 HERE

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 7). 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 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.

INSERT TABLE 7 HERE

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 underlying health conditions (UHCs). Overall, responses generated a total of 7 associated codes (sub-codes), resulting in 3 categories of meaning (see Table 8). 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.

INSERT TABLE 8 HERE

Key Findings:

- Findings 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 Post-Traumatic Stress Disorder (PTSD)
- Positive adaptation may promote post traumatic growth. In particular, health adversity is associated with greater appreciation.
- Emotional regulation is associated with post-traumatic growth (Appreciation and Strength sub-scales) for this population.
- PTG (Appreciation and Strength sub-scales) 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 (Cowden *et al*, 2021; Holmes *et al*, 2020; Vieira *et al*, 2020). Adults living with CHD already faced increased vulnerability to mental health problems pre COVID-19 (Kovacs and Bellinger, 2020) due to exposure to a number of unique psychosocial stressors and cardiac medical events that 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) (Vilchinsky *et al*, 2017). Further the relationship between cardiac health and trauma is bidirectional with studies reporting PTSD as a risk factor for heart disease (Edmondson *et al*, 2013). 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 (Cousino *et al*, 2020; Kwong *et al*, 2020; Umucu and Lee, 2020).

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 (Ruggiero *et al*, 2003). This is consistent with previous studies which highlight an increased prevalence of PTSD for in the CHD population (Deng, 2016) 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 (Morton, 2020). 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 (Cousino *et al*, 2020). 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 (Wray *et al*, 2012). Additional concerns about being able to access care during from the pandemic will potentially add to the burden of living with this condition.

Additionally, 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 Question 1 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 (Kamphuis *et al*, 2012). While compared to healthy adults even among the healthiest adults with CHD there are significant decrements in life expectancy, employment, and lifetime earnings (Gong *et al*, 2020). Categories of meaning and key codes derived from responses to the responses to the free text Question 1 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.

Further, negative media portrayals may increase psychosocial stress for the CHD population. Categories of meaning and key codes derived in response to the free text Question 2 regarding media coverage 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 fuelling 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 (Orejuela-Davila *et al*, 2019; Kira *et al*, 2020). 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 (Hays *et al*, 2020). Interestingly while 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.

Further, our findings suggest that for this population the Adverse and Traumatic Experiences subscale, Personal Health influences the PTG subscale, Appreciation. This finding should be interpreted with caution, in the context of a population who have lived with health adversity from ‘cradle to grave’ often being told they are ‘lucky to be alive’ (Morton, 2020). However, having faced lifelong adversity this population may experience positive adaptation through increased appreciation following adverse life experiences, consistent with previous PTG studies (Stellar *et al.*, 2015).

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 (Morton, 2020).

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.

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 undertreated (Kovacs and Bellinger, 2020). Findings also suggest that measures could be taken to promote positive adaptation for people with CHD. Specifically, emotional regulation seems to promote PTG which could be facilitated across the life journey through Psychoeducation and delivery of psychological therapy. 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 (Morton, 2020).

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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%		

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%

Table 4, Descriptive statistics

Variable	Mean	SD
PTGI Strength Subscale	10.36	5.14
PTGI Appreciation Subscale	8.64	3.76
PTSD-Checklist Diagnostic Scores	30%	.46
ERQ Internal Functional Subscale	1.79	.66
ERQ External Functional Subscale	1.74	.78
ERQ Internal Dysfunctional Subscale	1.41	.80
ERQ External Dysfunctional Subscale	.50	.42
ATES Personal Health Subscale	2.10	1.09
WAQ Controllability of Events Subscale	3.36	.91
GHSQ	3.85	1.14

Table 5, Means, standard deviations, and correlations with confidence intervals for PTGI Strength***

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1.ptg_strength	10.36	5.14							
1. PTGI Appreciation Subscale									
	1.79	0.66	.45**						
2. ERQ Internal Functional Subscale			[.34, .55]						
	1.74	0.78	.43**	.54**					
3. ERQ External Functional Subscale			[.32, .53]	[.44, .62]					
	1.41	0.80	-.17**	-.18**	-.28**				
4. ERQ Internal Dysfunctional Subscale			[-.29, -.04]	[-.30, -.06]	[-.39, -.16]				
	0.50	0.42	-.17**	-.23**	-.17*	.46**			
5. ERQ External Dysfunctional Subscale			[-.29, -.05]	[-.35, -.10]	[-.29, -.04]	[.35, .55]			
	2.10	1.09	.08	-.04	-.02	-.03	.02		
6. ATE Personal Health Subscale			[-.04, .21]	[-.17, .09]	[-.15, .10]	[-.15, .10]	[-.11, .15]		
	3.36	0.91	.22**	.24**	.17**	-.39**	-.14*	.01	
7. WAQ Controllability of Events Subscale			[.09, .34]	[.11, .35]	[.04, .29]	[-.49, -.28]	[-.26, -.01]	[-.12, .14]	
8. GHSQ	3.85	1.14	.11	.01	.06	.06	-.05	-.03	.05
			[-.02, .23]	[-.12, .14]	[-.07, .19]	[-.06, .19]	[-.18, .08]	[-.16, .10]	[-.08, .17]

Table 6, Means, standard deviations, and correlations with confidence intervals for PTGI Appreciation*.**

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6
1. PTGI (Appreciation)	8.64	3.76						
2. ERQ (Internal Functional)	1.79	0.66	.40**					
			[.29, .50]					
3. ERQ (External Functional)	1.74	0.78	.39**	.54**				
			[.28, .49]	[.44, .62]				
4. ERQ Internal Dysfunctional Subscale	1.41	0.80	-.19**	-.18**	-.28**			
			[-.31, -.07]	[-.30, -.06]	[-.39, -.16]			
5. ERQ External Dysfunctional Subscale	0.50	0.42	-.16*	-.23**	-.17*	.46**		
			[-.28, -.04]	[-.35, -.10]	[-.29, -.04]	[.35, .55]		
6. ATEs Personal Health Subscale	2.10	1.09	.12	-.04	-.02	-.03	.02	
			[-.00, .25]	[-.17, .09]	[-.15, .10]	[-.15, .10]	[-.11, .15]	
7. WAQ Controllability of Events Subscale	3.36	0.91	.12	.24**	.17**	-.39**	-.14*	.01
			[-.01, .24]	[.11, .35]	[.04, .29]	[-.49, -.28]	[-.26, -.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 $p < .01$.

Table 7: 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 cavilear 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

Table 8: 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.