**Title:** *“No official help is available”* - experience of parents and children with congenital heart disease duringCOVID-19

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**Abstract**

**Introduction**

The purpose was to explore the experience, information, support needs and decision-making of parents with congenital heart disease (CHD) during the COVID-19 crisis.

**Materials and methods**

A survey study of parents of children with CHD, children and young people, capturing experiences, decision-making, information and support needs during the COVID-19 crisis. The survey launched for 1 month (9thApril 2020) during the first infection wave in the UK and subsequent restriction of free movement under lockdown rules from March 23rd2020 until May 31st2020.

**Results**

184 parents and 36 children/young people completed the survey. Parents were more likely to worry about the virus (86.4%) than children/young people (69.4%), whilst (89%) parents were more vigilant for symptoms of the virus vs. children/young people (69.4%). A thematic analysis of the qualitative comments covered 34 subthemes, forming eight-overarching themes: Virus 1)risk of infection, 2)information, guidance and advice, 3)change in health care provision, and 4)fears and anxieties; Lockdown and isolation 5)psychological and social impact, 6)keeping safe under lockdown, 7)provisions and dependence on others, 8)employment and income.

**Conclusions**

There was widespread concern over the virus especially amongst parents. Parents and children/young people however, were frustrated with the lack of specific and paediatric focused information and guidance, expressing disappointment with the adult centric information available. Parents also felt alone, especially with their concerns around the implications of cardiac service suspension and the implication for their child’s health. In order to better support children and their families, resources need to be developed to address families’ and children/young people’s concerns for their health during this pandemic.

**Background**

In December 2019 a novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was identified ([1](#_ENREF_1)), and the subsequent rapid transmission of infection around the world resulted in the World Health Organization (WHO) declaring the outbreak of SARS-CoV-2 disease (COVID-19) a pandemic in March 2020 ([2](#_ENREF_2)). Despite the high infection rate amongst adults, children appear to be remarkably unaffected by COVID-19 (1-5% of cases) ([3](#_ENREF_3), [4](#_ENREF_4)), experiencing milder disease and significantly lower mortality rate ([4](#_ENREF_4)). In the first three months of 2020, governments of the majority of European countries implemented measures to slow the rate of infection, using social distancing and lockdown measures, lasting until early summer.

Congenital heart disease (CHD) represents one third of all major congenital anomalies, with a reported UK prevalence of 9 per 1,000 live births ([5](#_ENREF_5)). Of the 5000 reported CHD births, around 725 require interventional cardiac catheterisation and 4,000 need surgery per annum([6](#_ENREF_6)). The recent health crisis saw an unprecedented cessation of many Health Service outpatient clinics and all elective surgical procedures, including cardiac surgery suspended for three months from March 2020 until June 2020 ([7](#_ENREF_7)). The hiatus of usual paediatric cardiology services during this crisis period may have caused significant parental anxiety as well as unintended consequences due to delayed intervention ([8](#_ENREF_8)). The aim of this study was to explore experiences, information and support needs, and decision-making of parents of a child with CHD in response to the COVID-19 pandemic.

**Methods**

A survey study of parents of children with CHD, children and young people, capturing experiences, decision-making, information and support needs during the COVID-19 crisis was conducted. The survey launched on the 9thApril 2020 and closed on 9th May 2020, which was during the first infection wave of the COVID-19 pandemic within the UK and subsequent restriction of free movement rules from March 23rd 2020 until May 31st 2020. This study forms part of a larger longitudinal study describing experiences of parents and children with various paediatric conditions. The study was approved by the University of Southampton and NHS Health Research Authority Research Ethics Committees (Integrated Research Application System Reference 282176)

**Study participants**

Parents of children and children/young people with CHD were recruited through social media via social media platforms (Twitter, Instagram and Facebook) and national charities for CHD e.g. Children’s Heart Federation, British Heart Foundation, along with regional charities associated with each of the 10 national cardiac centres in the UK and Republic of Ireland. Children and young people between the ages of 12 and 25 years were invited to provide assent / consent to complete this survey, with parental consent for children younger than 18 years of age. All participants needed to be able to understand, speak and read English. Completion of the survey was voluntary and electronic consent was obtained through the online survey. A URL link with a generic message was created inviting parents to complete the SHARE Study was distributed via social media platforms. This approach was taken to minimise the burden on the health system during the COVID-19 outbreak and to recruit sufficient numbers of participants to describe the variety of concerns and experiences within closed statements, as well as common themes from the descriptive analyses of the rich qualitative data ([9](#_ENREF_9)).

**Survey**

The survey content is based on currently available literature ([9](#_ENREF_9), [10](#_ENREF_10)), expert health care professional input, and parents of children with CHD. The survey included the following sections with the number of closed statement items in parentheses: Experiences (9 questions), Information (4 questions), Decisions (6 questions) and Support needs (8 questions). Responses to the closed statement items were made using a Likert scale of Not at all (1), A little (2), Quite a bit (3), Very much (4). At the beginning of each section there was a free text box. The number of items was deliberately small, allowing for rapid analysis and dissemination.

**Data analysis**

Descriptive statistics summarising demographic data and responses to the closed statements were completed using IBM Statistical Package for Social Science (SPSS) (version 25, IBM, Armonk, NY, USA). Categorical or binary data were presented as raw values and percentages. Likert scale responses were reported as median and formed into two groups of (Not at all (1), A little (2)) and (Quite a bit (3), Very much (4)). Non parametric t-tests and Chi squared tests were used to test statistical significance which was taken as p<0.05. A thematic content analysis was used to explore responses to the open text boxes, informed by a three-stage coding process ([11](#_ENREF_11), [12](#_ENREF_12)): stage 1). An initial sample of 34 comments were open coded into broad comment categories by two researchers (SS and RW), an initial framework was compiled, and conflict around themes was resolved with a third researcher (ASD); stage 2) the best-fit framework guided categorization of all comments from the data (LVM), with further refinement (SS and RW); stage 3) overarching themes were identified. The number of comments was counted to identify the weight of themes. As there was considerable overlap in the rich data within the sections, the total number of comments did not match the number of participants.

## Results

*Participants*

*Parents*

One hundred and eighty four people completed the survey and included 92% (n=169) mothers, 8% (n=15) fathers/other guardians. The median age of children was 8 years old (Interquartile range (IQR): 3, 13) and parents was 40 years old (IQR: 33, 46). Children with CHD had a varying diagnosis with 17% (n=31) waiting for surgery and 83% (n=153) with no surgery planned. The geographic representation of respondents was well spread through the country with parents reporting from each of the four home nations of the UK (Table 1).

*Children and young people*

Thirty six children/young people completed the survey with a median age of 18 years old (IQR: 17,22). Thirty children indicated their age; 43% (n=13) were <=18 years old and 57% (n=17) were >=18 years of age. Children/young people with CHD had a varying diagnosis with 2.7% (n=1) waiting for surgery and 72.2% (n=26) were not waiting for any planned surgery (Table 1).

**Closed item statements**

*Parent*

Most parents worried about the virus (86.4%), and potential symptoms (89%), in addition to considerable concern regarding the ability of their child’s heart to cope if cardiac symptoms were triggered by the virus (88%). Respondents felt they did not receive adequate orsufficient information from their child’s clinical team (85%), and wanted information specfic to their child’s cardiac diagnosis (82%). Compared to parents of children with no planned surgery, those parents who were waiting for their child to have surgery were more likely to be worried about procedures being cancelled (p<0.001), in addition to wanting more information about the potential effects of the virus on their child’s heart (p=0.01) and more support from the specialist team (p=0.05) (Table 2; Supplementary File 1). Over half of parents felt their child should be isolated from everyone except parents (54%) and worried about health care professionals (HCPs) coming into the home (70%). Parents were worried they might catch the virus (63%) and if so, their child would catch it from them (85%). All parents accessed information on social media (100%), which for some (48%) led to anxiety. Three-quarters of respondents worried hospitals were no longer a safe place (77%). Planned appointments or surgery (84%) were rescheduled in consultation with the medical team, with a proportion of parents (16%) making the decision not to attend without consulting their team (Figure 1). Parents would welcome support to reduce their own worries relating to the virus (36%) and help to support their children (28%).

*Children and young people*

Worries of children/young people mirrored those of parents, although existed to a slightly lesser extent. Children/young people worried about the virus (69.4%), and were vigilant for symptoms of the virus (69%). The majority of respondents worried that hospitals were no longer a safe place (69%). Respondents felt they did not receive information they needed from their clinical team (64%), and would have wanted information specfic to their cardiac diagnosis (64%).

**Open text boxes**

 Overall, the responses from parents and children/ young people covered 34 subthemes, forming eight overarching themes, related to the virus (four themes) and lockdown/shielding or isolation (four themes): *Virus*: 1)information, guidance and advice 2)change in health care provision, 2)risk of infection, and 4)fears and anxieties; *Lockdown and isolation*: 5)psychological and social impact, 6)keeping safe during lockdown, 7)provisions and dependence on others, 8)employment and income (Table 2; Supplementary File 2).

***Virus***

The majority of parents (77%) offered comments. The number of comments was counted to identify the weight of themes, as there was considerable overlap in the rich data within the sections, the total number of comments did not match the number of participants (Table 2; Supplementary File 2).

*Parents*

Most comments concerned the virus (n=91), with the majority of respondents describing concerns about risk to their child’s heart and ability to cope or overcome infection with the virus, and how their heart or lungs would cope.

Parents reported that information and advice about clinical risk from COVID-19 was i) either non-existent or inconsistent within the four home nations, ii) was not specific to children iii) or their child’s CHD diagnosis. Parents reported feeling abandoned, lacking support from their child’s clinical team or The Government; and wanted reassurance they were not alone as well as official letters to show employers to allow them to stay at home and shield with their children (Table 2; Supplementary File 2).

***Lockdown and isolation***

Parents described a significant psychological impact of the emergence of the virus and subsequent periods of lockdown, on themselves and their children, raising concerns about keeping their child safe. An example were parents working as frontline health workers who chose to live separately from their family in order to keep them safe.

***Information***

Parents reported having accessed information from a number of sources including; CHD specific sources including, British Heart Foundation, Children’s CHD charities and the British Congenital Cardiac Association; in addition to news outlets NHS/ Government websites, World Health Organisation and social media.

***Support***

Parents wanted more support to gain eligibility to access priority on-line grocery shopping delivery slots as well as instructions for re-integration as to what to do when lockdown restrictions are lifted

**Decisions**

Most parents (n=92) did not rely on official advice regarding clinical vulnerability and took the decision to keep their child at home ‘shielded’ based on ‘gut instincts’ and relying on their own judgment.

***Children and young people***

The majority of children/young people (70%) offered comments.

*Virus*

 Most comments from children/young people described a fear of contracting the virus and not recovering, although some had no concerns. Children/young people wanted more information specific to their cardiac diagnosis and almost half of them had not left home since lockdown began. Children/young people would have liked more support with information specific to their cardiac diagnosis (Table 2; Supplementary File 2).

***Lockdown and isolation***

Children/young people reported feeling sad, panicked, bored, isolated and missing their friends (Table 2; Supplementary File 2).

***Information***

Information sources for children/young people were parents, news sites, although children reported worry and concern about conflicting/ untrustworthy information.

***Support***

Children/young people would have liked more support with mental health and well-being and support with school or decisions around college.

**Decisions**

The majority of children/young people described trying to keep safe by staying indoors, sanitizing hands and the family home. A number of children were grateful for the study being conducted, as they felt they were often forgotten or overlooked.

**Discussion**

To our knowledge this is the first study to report the experiences of parents of children and experiences of children/young people with CHD during the COVID-19 crisis. The majority of parents expressed an overwhelming sense of worry about the effects of the virus, and the potential impact this may have on their child’s heart should they contract the illness. This worry also resonated amongst children/young people, although fewer were as concerned about the virus and some children were able to rationalize that adolescents did not appear to be significantly affected by the virus. Results from a large prospective observational study of depressive and anxiety levels in adults (n=70,000) during and following the first national lockdown (March 23 to August 9) suggest the highest levels of anxiety and depression coincided with the early period of restrictions, but declined rapidly thereafter. However, Fancourt *et al* emphasised the need to better support those with poorer mental health, as they most severely affected by future periods of national lockdowns. As such parents of children with long term health conditions may represent those indivduals described as being at greater risk of poorer mental health during, and subsequent to, periods of lockdown, and strategies to better support families need to be developed ([20](#_ENREF_20)).

The majority of parents surveyed electively withdrew themselves and their children with CHD and other family members from society before or immediately as the government lockdown was initiated. Reasons for this were fear of the unknown effects arising from a lack of specific information, and distrust in the adult-centric advice given. This was similarly echoed by children/young people who wanted paediatric-specific information.

Some of the children/young people included in this survey had unrepaired or palliated CHD, but many had haemodynamically inconsequential lesions, and it is striking that even these families experienced uncertainty and anxiety related to their CHD-associated risks. Parents of children awaiting surgery were more likely to be worried about elective procedures being cancelled, in addition to wanting more information about the potential effects of the virus on their child, as well as wanting more support from the specialist team .

Although clinical teams provided support to parents and children/young people with CHD, providing available information during the COVID-19 crisis, this is not how it was perceived by parents, particularly with respect to letters to support them being able to stay at home with their children. Further to this, parents felt abandoned and alone, especially with their concerns around the implications of cardiac service suspension and the implication for their child’s health. Concerns regarding perceived vulnerability of their children may have been further exacerbated following reports of COVID-19 or COVID-19 like symptoms with hyperinflammatory multisystem syndrome temporally associated with COVID-19 (PIMS-TS) and atypical Kawasaki disease**(**[**14**](#_ENREF_14)**); as such it is important for the health care community to recognize the potential psychological impact media reports may have on parents of children with** CHD([15](#_ENREF_15)), and their increased vulnerability as a result. Of particular concern is the proportion of parents and children/young people (around three quarters) who were concerned about the safety of visiting hospitals and, to a lesser degree, about receiving visits from health professionals.

Children/young people reported feeling panicked, isolated and missing their friends, as well as feeling sad and bored. There are profound consequences for the mental health and well-being of children as a result of social distance strategies to contain the spread of the virus([16](#_ENREF_16)); in addition there may be long-lasting consequence of educational poverty and diminution of educational opportunities arising from school closures([17](#_ENREF_17), [18](#_ENREF_18)), which may more adversely affect children with serious conditions. Findings from this and the SHARE study exploring the views of parents of children with cancer have highlighted parents were worried about the virus in the context of their child’s disease condition, with government restrictions impacting on their ability to see family and friends ([19](#_ENREF_19)).

***Study limitations***

There are a number of limitations of this work including the use of social media to recruit participants. This method of recruitment may have resulted in the small sample size and potentially excluded those individuals with digital poverty, literacy and language issues. Although charities and support groups of children with CHD were targeted, some groups of patients might have been overlooked, particularly those with less severe congenital heart defects, thus imposing sample bias. The survey also represents a maternal view-point as the majority of respondents in the adult survey were women.While we believe that our results can be applied to the CHD population as a whole, it is important to acknowledge that respondents were more representative of more severe and complex conditions, i.e., those who might have been more concerned about the impact of the COVID-19 virus. It is possible that parents and children/young people who regarded themselves as more clinically vulnerable were more likely to respond to the invitation to participation as they perceived the survey as relevant to them. A comparison between sub-groups of participants according to the severity of the CHD lesion as well as with the general population would have been very insightful and could represent a future avenue for research.

Despite these limitations we believe the findings of this survey are important and demand a considered approach as to how parents and their children with CHD are better supported in the future, particularly if further periods of social distancing measures are required which result in closure of schools. Larcher *et al* ([18](#_ENREF_18))propose that article 12of theUnited Nations Convention on the Rights of the Child([21](#_ENREF_21)) should be invoked requiring, ‘*children to be informed and consulted over matters that concern them and that their views be given due weight in accordance with their age and maturity’* and is in keeping with the NHS ethos of ‘*no decision about me, without me’*. For the future, it is imperative we ensure better support and information for families to reduce the effects of social isolation, medical and educational deprivation.

***Lessons learnt – How to address them***

1. ***Development of Children’s focused CHD information***: This pandemic has raised many societal issues relating to how children are treated and viewed during a pandemic ([18](#_ENREF_18)), and the interests of children, particularly those with complex health and social needs, should be at the heart of any recovery plan to get back to normal or ‘new normal’ Perhaps as part of this process we need to start by providing children with specific information relating to the effects of COVID-19 on children as a whole, as well as in the context of those with serious conditions. Our survey suggests parents of children with CHD, as well as children/young people feel scared, abandoned and frustrated at the lack of bespoke information that talks to them about them during the COVID-19 crisis.
2. ***Technology enabled care services***: Safety fears might have contributed to parental decisions to cancel medical appointments. In addition, avoidance of face to face contact with health care professionals might translate into feelings of greater isolation and a perception of less support from the clinical team. It is thus imperative to consider ways in which parental concerns can be allayed, for example, written or verbal information about measures put in place to keep their child and themselves safe during visits. Clinical teams have had to establish new ways of working to protect patients and look for subtle changes in clinical status particularly with consultations carried out over the telephone or via technology enabled care services becoming the primary mode of clinical review.
3. ***Trustworthy information***: In the advent of often contradictory information with regards to the effect of COVID-19 pandemic on children’s safety; there is a need to work with communication and education specialists, to develop accurate, trustworthy, consistent and accessible information for *all* children, but in particular for those with long term health conditions ([13](#_ENREF_13)). Trusted charities and Government health websites and social media may be used to disseminate this information.

**Conclusion**

Parents were worried about the potential effects of the virus on their children’s heart, as were children/young people although to a lesser extent. Parents felt unsupported, abandoned and frustrated with the lack of specific and focused information and guidance, expressing disappointment with the adult centric information. In order to better support children and their families, developed resources need to address families’ concerns for their children’s health during this pandemic.

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None

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None

**CONTRIBUTORS STATEMENT:**

Authors made the following contribution to the manuscript: (1) Anne-Sophie Darling formulated the original idea and wrote the study design including the survey, (2) Luise Marino, Richard Wagland, Samantha Sodergren, Anne-Sophie Darlington, David Culliard analysed the data, (3) Luise Marino drafted the manuscript, (4) Tara Bharucha, Richard Wagland, Samantha Sodergren, Anne-Sophie Darlington contributed to revising the manuscript for important intellectual content, (4) and all authors provided final approval of the version to be submitted.

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**Table 1a: Parental reported demographics and CHD diagnosis**

|  |  |
| --- | --- |
| **Parental Respondents – region of residence**  | **% (n=184)** |
| Northern Ireland Scotland Wales United KingdomSouthern England Northern England  | 20.1% (37)5.9% (11)7.0% (13)10.8% (20)36.4% (67)19.5% (36) |
| **Parent reported diagnosis** | **% (n=184)** |
| ASD, VSD or AVSD | 13.0% (24) |
| Pulmonary stenosis | 5.4% (10) |
| TOF or DORV | 17.4% (32) |
| Left heart obstruction | 14.7% (27) |
| Transposition of the great arteries | 11.4% (21) |
| Univentricular heart physiology | 26.1% (48) |
| Ebstein’s anomaly | 0.5% (1) |
| Other complex CHD | 8.2% (15) |
| Cardiomyopathy or cardiac transplant | 2.2% (4) |
| Complete heart block | 1.6% (3) |
| Long QT syndrome | 1.1% (2) |
| Parental reported diagnosis – waiting for surgeryHypoplastic left heart/ Pulmonary atresia/ ventricular septal defect/ double outlet right ventricle/ TGAVentricular Septal Defect Transposition of great arteries (TGA)Aortic stenosisAtrio ventricular septal defectTetralogy of FallotTricuspid atresiaMitral valve regurgitation/ vascular ring/ atrial septal defect |  7% (31)35.4% (11) 23% (7)10% (3)10% (3)7% (2)7% (2)4% (1)\_4% (1) |

**Table 1b: Children/ Young people reported demographics and diagnosis**

|  |  |
| --- | --- |
| **Children/ Young people reported diagnosis** | **% (n=36)** |
| Waiting for surgeryNo surgery plannedDon’t know | 2.7% (n=1)80.5% (n=29)16.7% (n=6) |
| VSD | 11.1% (4) |
| Pulmonary stenosis | 2.7 % (1) |
| TOF | 2.7% (1) |
| Left heart obstruction | 11.1 % (4) |
| Transposition of the great arteries | 16.6% (6) |
| Univentricular heart physiology | 13.8% (5) |
| Ebstein’s anomaly | 2.7% (1) |
| Congenital heart disease/ don’t know | 50% (13) |

ASD: atrial septal defect; AVSD: atrioventricular septal defect, CHD: congenital heart disease; DORV: double outlet right ventricle; TOF: tetralogy of Fallot; VSD: ventricular septal defect

**Table 2: CHD: Experiences of Covid-19: Table of themes from 141 comments from a total of 184 parent respondents (76.6% of total respondents) and 24 comments from 36 Children/ Young People (66.6%)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Theme**  | **Subtheme**  | **Number** | **Number** |
| **VIRUS** |  |
| 1. **Risk of infection**
 | Concern over child’s low immunity | 41 | 16 |
| Concern over visiting hospitals | 9 | 3 |
| Decision to remove child from school prior to lockdown | 10 | 12 |
| Family member has / had Covid-19 | 5 | 3 |
| Concern over infection entering the home from parent having to work or shop for provisions  | 25 | 5 |
| Vigilance of symptoms of virus infection | 1 | 3 |
| 1. **Information, guidance and advice**
 | Limited information/ mixed messaging | 56 | 12 |
| Need for targeted advice and support | 9 | 6 |
| Information regarding child’s vulnerability status not issued | 66 | 3 |
| Feel need to seek info from other sources | 5 | 16 |
| 1. **Healthcare provision**
 | Concern over sub-optimal treatment and care might be missed  | 32 | 2 |
| Lack of contact from cardiac team | 31 | 2 |
| More support required | 11 | 4 |
| New ways of working in the hospital | 2 | 1 |
| Hospital facilities strained | 3 | 2 |
| 1. **Fears and anxieties**
 | General expressions of fear | 8 | 3 |
| Concern over ability to look after child if parent ill or dies | 2 |  |
| Concern child or parent will die | 18 | 1 |
| Things could be worse  | 4 | 4 |
| Separation if child becomes ill from rest of family | 1 | 5 |
| Child has had/possibly had Covid-19 | 5 | 3 |
| **LOCKDOWN AND ISOLATION** |  |  |
| 1. **Psychological and social impact**
 | Psychological impact on child and family, missing out on life, boredom | 32 | 4 |
| Parental coping (struggles, strategies used) | 25 | 3 |
| Missing family and friends | 4 | 12 |
| Impractical nature of social distancing | 4 | 5 |
| Social and educational development | 8 | 3 |
| Missing emotional support for parents from friends and family | 1 | 12 |
| Separation from partners/parents/children | 2 | 3 |
| 1. **Keeping safe under lockdown**
 | Concern over societal compliance in social distancing in society and delayed lockdown  | 12 | 6 |
| Being on lockdown keeps child safe | 4 | 6 |
| Concern once restrictions are lifted/ adjustment concerns | 7 | 4 |
| 1. **Provisions and dependence**
 | Difficulty securing provisions (food, cleaning, medication) | 14 | 1 |
| Lack of priority status | 5 | 5 |
| Reliance on friends and family to pick up provisions | 3 | 3 |
| 1. **Employment and income**
 | Concern over job/ job loss | 11 | 4 |