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Experiences of siblings of children with congenital heart disease during Coronavirus disease 2019; A qualitative interview study

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ABSTRACT

Purpose: To explore siblings' perceptions of having a brother or sister with congenital heart disease in the UK during the COVID-19 pandemic.

Design and methods: Siblings of children with congenital heart disease aged 8–17 years old were interviewed via video call technology between September 2020 and February 2021. We conducted reflexive thematic analysis of these interviews to generate themes.

Findings: Interviews took place with 17 siblings, predominantly of white ethnicity $n = 15$ (86%). Most siblings interviewed were first born in the family $n = 15$ (88%), and most children with CHD were the youngest $n = 15$ (88%). Four themes were generated; My sibling is vulnerable, what does this mean for my family, I have a responsibility to protect my brother or sister, our family time during the pandemic and adjustment and adaptations to pandemic life.

Conclusions: Siblings identified difficult aspects of the pandemic and these related to concerns about their brother's or sister's vulnerability, family impact, and keeping their sibling safe. They also identified adjustments they made to keep their family functioning throughout the COVID-19 pandemic. Despite the worry and uncertainty siblings experienced, they valued increased family cohesion which helped to mitigate some challenges of the restrictions imposed in the UK.

Practice implications: Honest and open communication is valued by siblings. It is vital to ensure siblings receive the support they need to ensure they keep up with their schooling and social commitments as pandemic related restrictions ease.

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Introduction

Congenital heart disease (CHD) is a developmental abnormality which results in problems with heart walls, valves or blood vessels (Schwerzmann et al., 2016). Worldwide prevalence of CHD is 1.35 million new-borns per annum (van der Linde et al., 2011) and 0.55% of live births in the United Kingdom (UK) (Townsend et al., 2013). Significant improvements in medical and surgical care now enable children with CHD to live longer (Stout et al., 2016).

CHD is associated with developmental delay and psychological problems (Marino et al., 2012). Children with CHD are at risk of comorbidities which may lead to disability or chronic illness resulting in a long-term impact on health (Knecht et al., 2015). Even if a heart defect is repaired, there can be a life-long burden with quality of life affected. A child with CHD is supported and cared for within a family, by parents and siblings; therefore, a long-term care burden also lies with them (Knecht et al., 2015).

Responsibility for caretaking is commonly viewed as joint between family members (Avieli et al., 2019). As parents age siblings may become primary caregivers (Wofford & Carlson, 2017). This is often seen as an expected part of their family role and future (Heller & Arnold, 2010). A family may incur additional financial costs, some may be required to perform medical care at home, be involved in complex

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medication routines, and need to make frequent clinic visits (Woodgate et al., 2016). The effect of this on siblings of children with CHD remains unknown (Parker et al., 2020).

Sibling relationships create a unique bond, outlasting that of parents or friends (Cicirelli, 2013). Sibling roles and relationships are formed through a dynamic process with a contribution of all family members (McHale et al., 2012). Siblings describe their relationship with their brother/sister with a disability as positive, nurturing and satisfying (Burbidge & Minnes, 2014). Whilst celebrating positive aspects of having a brother/sister with chronic illness, siblings need support in accepting their circumstances and finding ways of coping. This is essential as they develop into young adults (Deavin et al., 2018).

Some data are available on the impact of siblings with chronic diseases. There is evidence that different illnesses have different influences on siblings, highlighting a need for disease specific research (Houtzager et al., 2001; Sharpe & Rossiter, 2002; Vermaes et al., 2012). A recent review focusing on the specific impact on siblings of children with CHD found that siblings experience adverse life changes which lead to negative impacts in many areas of a child's life (Parker et al., 2020). Little is known about mitigating factors and much more specific evidence is required. Research focusing on siblings of children with CHD is essential for identifying, developing and delivering targeted services to children and their families (Ingerski et al., 2010).

This article explores siblings' perceptions of having a brother or sister with CHD in the UK during the COVID-19 pandemic. Findings are based on qualitative data collected during the pandemic, as part of a wider study called the 'heArt sibLings ImPact Study (ALPS). To our knowledge no previous research exploring the impact of COVID-19 on siblings of children with CHD has been published.

Aim

To explore siblings' perceptions of having a brother or sister with CHD in the UK during the COVID-19 pandemic.

Design and methods

ALPS is a sequential exploratory two-phase mixed methods study exploring the impact on Children and Young People (CYP) who have a sibling with CHD. In line with mixed methods design principles, the phase one qualitative data collected using an exploratory interview study, informed the phase two survey currently being undertaken (Creswell & Poth, 2016). Throughout this article we have followed the Consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007).

Theoretical framework

ALPS is underpinned by Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1992), chosen because it observes and places value on specific bioecological systems which surround a child. These systems, in an order starting with those most proximal to the child, are: immediate family; followed by extended family, peers, school life; followed by healthcare interactions, cultural and religious influences; and finally recognising changes over time (Bronfenbrenner, 2005). Those systems closest to a child are thought to have more impact on health and development (Joly, 2015).

Sample and setting

Three UK cardiac charities advertised the study by sharing posts on their social media pages, newsletter, and regular virtual support meetings. Siblings aged 8–17 years old were eligible to take part if they were UK based and lived with their brother or sister with CHD. Participants also needed to be able to read and speak English as funding was not available

for interpretation. Siblings of children with acquired heart disease or who had experienced a bereavement were not included.

Data collection

Semi-structured interviews via Zoom (Zoom Video Communications, Inc., San Jose) enabled exploration with different respondents in a systematic way (Jamshed, 2014). Interview structure was based on a topic guide which focused on the impact of having a brother or sister with CHD. We asked questions about their brother or sisters heart condition, how it affects daily life, what happens when they go into hospital, and any memories they have which are good or difficult. We also asked what advice they may give to another sibling about what life is like, what they would like to be different and what support might be helpful. The interview guide was adapted depending on age/stage of development and on maturity of the CYP. It was important to ask specific questions about how life was different during the pandemic to ensure overall impact about having a brother or sister with CHD was about pre-pandemic life. Due to the changing nature of the pandemic and different geographical locations of participants, some exploratory questions were asked about how their lives had been different during this time, before asking more specific questions about impact. An interview guide helped keep interviews on topic whilst allowing for participants to freely discuss related content. This approach maximises content without running into long interview timings, which may place additional burden on participants (Creswell & Poth, 2016). Interviews lasted around 30 min on average.

Rapport building is an essential aspect of interviews and may influence data (Roulston, 2019). During online interviews rapport building was more challenging, this observation is shared by other researchers doing online interviews (Seitz, 2016). To overcome difficulties with rapport building the child's physical environment was used as a discussion point and began the interviews asking about a child's school, family and their hobbies and interests. Sometimes this facilitated them showing us their favourite toys or their Lego models which gave the interviewer tools to use to keep questions relevant to the child. For example, "Can you take your Lego to hospital when you visit your brother?"

Data analysis

Following transcription, anonymized interview data were thematically analyzed by the lead author (XX blinded for peer review) using an inductive and reflexive approach detailed by (Braun et al., 2019). Familiarization occurred by listening again to recordings and reviewing reflective notes from each interview. A review of transcripts enabled early coding using QSR International Pty Ltd. (2018) NVivo (Version 12). Any data mentioning COVID-19, the pandemic and related experiences such as social distancing, lockdowns, school closures, vaccinations and recognising the sibling with CHD as being medically vulnerable and shielding/self-isolating were coded. Data were first coded by (XX blinded for peer review), then reviewed and discussed as a team to determine final themes. When using quotes within the text pseudonyms have been used to maintain confidentiality but also to add context to data.

Reflexivity

The interviewer has a nursing background but no recent experience in cardiac care. She has experience interviewing children and young people for research projects. During this study period the interviewer would not have provided nursing care to any child or family participating. All participants were introduced to the researcher via video call, to ascertain understanding the researcher asked CYP to explain what they understood about the research study. This enabled an opportunity for clarification and to answer any questions.

Ethical considerations

Ethical permissions were granted from XXX (blinded for peer review) - ETH1920-0081. The study was advertised by three national cardiac charities and families made contact via email if they were interested to learn more. Information sheets were sent along with an invitation containing a quick response code to a YouTube video with more information. An opportunity for questions was provided by email or telephone in view of social distancing measures.

If siblings and their parent/guardian agreed to be involved, signed consent and assent were taken from both the parent and child at the start of the video interview and completed forms were returned to the interviewer in a self-addressed envelope. It was important to have contact with CYP directly prior to starting the interview to ensure they fully understood our study information. It was vital to ensure they were adequately informed before giving their permission to be involved, assent was an essential part of this study and its importance is supported in research with CYP (Oulton et al., 2016).

Conducting virtual rather than face to face interviews during the pandemic avoided the research process being delayed. However, it was imperative that children could still be kept safe, have their data protected, privacy respected, and their support needs met (Vaughn, 2020). To start the interview, parents were present for consent and asked to be on hand if their child became distressed or the interview process left them with questions. Parents were also asked to leave their child to be interviewed privately. This was stipulated in parent information sheets and emails prior to interview. It was important for children to feel that they could speak freely.

Provision for support needs and parental presence at home during interviews were especially important as an online format meant the researcher could not be physically present. On the following day participants were emailed to check and see if the family had any questions or support needs. Signposting was also offered to charities and support services if families felt it would be beneficial. Interviews were visibly emotive for some participants. In such cases, opportunity to stop, take a break or have parents present was provided. As the interviewer was not physically present, it was important to ensure parents were physically available for support so on those occasions the interviewer asked for the parent to be called back at the end. The interviewer asked participants how they felt after talking, did they have any questions and did they need any support. There were no safeguarding concerns raised during the interviews, but the interviewer had more frequent contact with parents after a child became upset to make sure their family were aware of support services. Siblings and parents of children who became distressed reported the importance of siblings' voices being heard and valued an opportunity for them to share this whilst participating.

Findings

Interviews took place with 17 CYP aged between 8 and 17 years old. Most CYP interviewed were first born in the family $n = 15$ (88%), and most children with CHD were the youngest $n = 15$ (88%). See Table 1 for a summary of demographic information.

Four COVID-19 related themes were generated detailing the impact on siblings of having a brother or sister with CHD during the COVID-19

Table 1
Demographics information.

Gender	Male – 6 (35%)	Female – 10 (59%)	Non-Binary 1 (6%)
Age (years old)	M (SD) 11 (3)		
Ethnicity	White – 15 (88%)	Mixed – 1 (6%)	Asian/Asian British - 1 (6%)
Co-morbidities present in child with CHD	Yes – 11 (65%)	No – 6 (35%)	
CHD Classification	Biventricular physiology – 10 (59%)	Single ventricle physiology – 7 (41%)	
CHD diagnosis	Postnatal – 1 (6%)	Antenatal – 16 (94%)	
Sibling visited brother/sister in hospital	Yes – 13 (76%)	No – 4 (24%)	

pandemic. These were: My sibling is vulnerable, what does this mean for my family; I have a responsibility to protect my brother or sister; our family time during the pandemic; and adjustment and adaptations to pandemic life.

My sibling is vulnerable, what does this mean for my family?

All siblings classified their brother or sister as vulnerable, including to contracting COVID-19, in the context of their physical symptoms, medications, co morbidities or because of their mental health. All siblings discussed a lack of information related to COVID-19, particularly worrying as they identified their sibling as vulnerable, which then had an impact on them. Emma (14 years old) explained *“In the beginning we didn't know anything about it, so my mum took us out of school”*.

Most siblings identified their role in keeping their family functioning during lockdown. This meant meeting care needs of their brother/sister and helping with chores to facilitate their parents working from home. As one sibling explained *“because my sister can't leave the house, she (mum) runs to the shop and leaves her with me for 5 mins, but I worry something might happen”* Lucy (13 years old).

A few siblings spoke about a balance between keeping informed and being fearful and worried when keeping up to date with news, as Lucy aged 13 explained *“I watched the news because I wanted to be kept informed, but I didn't want to be worried so sometimes I switched it off”*. It was important to understand current recommended health advice to ensure they were doing all they could to protect their brother or sister from the virus. This was made clear by Luke (10 years old), who stated *“I always need to know the accurate information, so I know what to do”*. Most explained that they understood that the effects of the virus could be much worse for their sibling than if they caught it themselves, Zain (11 years old) explains *“well I feel like I have to be extra careful because even if I get it, it could be fatal but if (my brother) gets it, it's gonna be really serious”*.

I have a responsibility to protect my brother or sister

Most siblings explained their responsibility to protect their brother/sister from the virus. This involved keeping themselves informed about government guidance, following rules, and shielding. Considerable guilt was anticipated by siblings of children with CHD. They recognised that passing the virus to their brother or sister would not be intentional, but they would feel responsible and guilty if anything happened, Sally (15 years old) said *“What if I got it and gave it to her, I would never forgive myself.”* Most siblings also demonstrated that they prioritized their siblings' needs over their own, Gary (11 years old) explained *“I want to keep myself safe but I'm mostly doing it for my brother.”*

Fears about the virus, its spread, and effects of illness on their brother or sister were also considerable. These feelings of fear were felt more acutely when children were advised by the government to return to school as Tara (15 years old) described *“I'm so worried especially being back at school you have no idea who might have it.”*

Most children spoke about family routines adopted to protect the child with CHD from COVID-19, these included keeping clean, isolating within their family home if they felt unwell and keeping physical distance. Adam (11 years old) spoke about his routine being unmanageable then as there was so much to do. He explained this in more detail

“like if any of us have it (COVID-19) we want to get it off of us because we don't want (my brother) getting it so we have showers and baths and like brush our teeth and wash all of our phones and face masks and face shields and then wash all of our clothes.”

Our family time during the pandemic

Siblings all discussed positive and negative aspects of spending more time with their family. Some found shielding boring and did not enjoy so much time indoors. Aida (9 years old) explained *“Shielding at home is boring, we are driving each other crazy.”* Luke (10 years old) valued time alone with his parents, *“My sister's school opened before mine, so I got to spend time with mummy and daddy.”* Many referred to their busy lives before COVID-19 with travelling to hospital appointments and juggling school and social activities, much of which was converted online or had to be cancelled during the pandemic. This enabled more time to be spent together as a family playing games, taking walks, and just having time to talk - something they hoped would continue once restrictions were lifted. Lisa (12 years old) confirmed some of the positives of having more time together as a family *“I think it's brought us together more and we go on family walks together a lot. So, it's getting us fitter and healthier, and we're spending more time together.”* However, not all families were together and COVID-19 restrictions prevented physical contact with extended family, Sally (15 years old) explained *“We have family who don't live in England, so we haven't been able to see them.”*

Adjustment and adaptations to pandemic life

Most siblings discussed how they had adapted to things being different to the point of forgetting how life was before as explained by Ritika (8 years old), *“I don't remember the other life I had.”* Although initial adjustments were a challenge, siblings recognised that this was true for all members of the family as Adam (11 years old) commented, *“It's hard for my mum she was working from home and doing our school stuff and looking after us.”* Some siblings accommodated adjustments which were mostly increasing their caretaking duties and household chores within the home to keep their family functioning, as Aida (9 years old) explained *“because my dad was stuck up there doing his work, so I made everybody lunch and then my dad helped me a bit with some of the lessons.”* However, a few siblings explained that this was not sustainable and had an impact on their academic commitments as was the case for Paula (15 years old), *“Because I have to look after my sister when my parents are working, I have fallen behind with school stuff”.*

Discussion

Findings from this study highlight the impact of COVID-19 on siblings during a specific time of global crisis. The limited available evidence suggests that these children experience difficulties with schooling, increasing caretaking duties and household tasks, emotional challenges, and a feeling of responsibility outside of a pandemic (Parker et al., 2020). What is clear from our study is that the COVID-19 pandemic may have intensified these issues for siblings of children with CHD. Four themes were generated from the interview: My sibling is vulnerable, what does this mean for my family, I have a responsibility to protect my brother or sister, our family time during the pandemic and adjustment and adaptations to pandemic life.

Many families who have children with a heart condition are concerned about the impact of COVID-19 on their children (Hemphill et al., 2020). There is a distinct lack of information about how children with underlying conditions may be affected by COVID-19 (Sinha et al., 2020). Parents accepted this initially, appreciating it as a novel virus, but inconsistent or conflicting information was found to be concerning (Cousino et al., 2021; Wray et al., 2021). This lack of information, fear about COVID-19 and the impact this illness may have on their sibling

was clearly expressed by participants in this study. Children with CHD are thought to be at increased risk due to their more limited cardiopulmonary reserve, but this depends on the severity of CHD and status of their surgical repair (Malviya & Yadav, 2020). Recent data from the United States of America suggests that children with CHD who have COVID-19 are more likely to experience a longer hospital stay, higher rate of complications and have a higher mortality rate than children without CHD (Strah et al., 2021). During the early stages of the pandemic the UK government urged those who were ‘medically vulnerable’ to isolate while more information was gathered. What siblings reported as confusing was a lack of guidance about what ‘medically vulnerable’ means and who it applies to.

Despite the lack of clarity, all siblings termed their brother or sister with CHD as vulnerable, which may be as a result of widespread concern among the CHD community and many families choosing to ‘self-isolate’ or ‘shield’ just in case. This caution is supported by a lack of evidence about COVID-19 for paediatric patients with CHD (Tan & Aboulhosn, 2020), which may reflect a reduced incidence of COVID-19 in this specific group. However, limited knowledge during a time of global concern feeds concerns and worry, something siblings of children with CHD spoke about openly during interview and which others have identified (Asbury et al., 2021; Plante, 2020). This has also been reported for adult siblings of disabled children in a survey by the UK based charity ‘Sibs’, in which 91% reported that the COVID-19 pandemic had made their life more challenging (Sibs, 2020).

Recent literature highlights collateral damage affecting children during the COVID-19 pandemic (Crawley et al., 2020; Feltman et al., 2020). Children are thought to have been hit hardest psychosocially (Ghosh et al., 2020). Children with existing mental health problems, disabilities, and those from migrant or low socioeconomic backgrounds are more likely to experience collateral damage caused by the COVID-19 pandemic (Fegert et al., 2020). Adverse psychological and psychosocial outcomes for CYP during the pandemic have been widely reported (Gassman-Pines et al., 2020; Jiao et al., 2020; Patrick et al., 2020; Yeasmin et al., 2020). Conversely Bailey et al. (2021) found that siblings of children with intellectual disabilities report similar internalising and externalising behaviour pre and post lockdown.

During periods of national and regional UK lockdowns children were mostly confined to their homes with school closures, lack of outdoor activities, which was especially challenging during winter months, and a distinct lack of routine (Ghosh et al., 2020). This monotony likely caused distress, irritation, and other strong negative emotions (Ghosh et al., 2020), and this was also described by siblings in our study. For children living in small spaces or overcrowded housing this is likely to have been a greater challenge (Rosenthal, Ucci, Heys, Hayward, & Lakhnypaul, 2020). Siblings spoke about being bored and the irritation within the family but conversely reported enjoying having more time together, something they hoped would continue after restrictions were lifted. Such benefits have also been described for other groups (Magis-Weinberg et al., 2021; Williams et al., 2021).

There is also evidence of heightened parental stress during the COVID-19 pandemic (Brown, Doom, Lechuga-Peña, Watamura, & Koppels, 2020). A study in Germany identified a deteriorating family situation, more behavioural difficulties among children and usual family conflicts escalating more quickly in comparison to pre pandemic times (Ravens-Sieberer et al., 2021). Links between parent stress and a child's negative emotional regulation have been identified (Spinelli, Lionetti, Setti, & Fasolo, 2020). Parents of children with CHD specifically report experiencing baseline stress in diverse ways (Sood et al., 2018). Additional stressors related to a global pandemic could arguably increase parental stress and increase family tensions which may adversely affect the emotional wellbeing of siblings (Creswell et al., 2021, Plante, 2020). Although siblings in our study did not explicitly describe how they were affected by any increased parental stress, they did report increased disruption to their lives due to the need to provide additional care to their sibling and support to their parents.

Strengths and limitations

This study provides a unique insight into the lives of siblings of children with CHD during the COVID-19 pandemic. Baseline data on sibling impact is lacking but during the COVID-19 pandemic this impact appears to have been intensified. Shielding may have provided an opportunity for siblings to share their experiences with the researcher when otherwise they may have been too busy to participate. Somewhere private to talk may not have been possible for some families and it was impossible to see beyond the webcam lens to guarantee that siblings had privacy, this may have an impact on what siblings felt they could disclose and must be considered when interpreting findings. Reporting COVID-19 data was not a primary aim of the ALPS study; however, interviews were adapted to include questions relevant to the COVID-19 period and participants were given an opportunity to talk freely about issues affecting their life to date. This small and specific pool of CYP who shared their experiences from the UK may not reflect experiences of other children in similar situations across the world as COVID-19 specific restrictions were different depending on geographical location. Another limitation of the study was using charities as a sole source of recruitment. These participants engaged in support via the charity and may have received more support and information, and felt less isolated, than those who did not access charity support during the pandemic.

Practice implications

Findings highlight the impact of the COVID-19 pandemic on siblings of children with CHD. It is vital to ensure siblings receive the support they need to ensure they keep up with their schooling and social commitments as pandemic related restrictions ease. Charities are well placed to support siblings, cardiac charities were found to be a great source of support and information throughout the pandemic (Wray et al., 2021). Healthcare professionals also need to ensure clear and honest communication with families. Educational services need to appreciate the unique challenges siblings face, especially those who have had to take on extra caring and household duties to keep their family functioning during the pandemic. Siblings who identify as carers or who undertook caring duties during this time will need additional support to keep up with their academic work and to mitigate any impact on future career prospects.

Conclusions

Qualitative interview data collected from siblings of children with CHD during COVID-19 have identified CYP's perceptions of the impact of the pandemic on daily life. Siblings worried about their brother's or sister's vulnerability, keeping them safe and how it affected their family as a unit. Despite worry and uncertainty siblings experienced, they valued increased family cohesion, which helped mitigate some challenges. Further studies exploring the collateral damage of COVID-19 among specific disease groups could provide important information to support the holistic health of families.

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Declaration of Competing Interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the

criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

We understand that the Corresponding Author is the sole contact for the Editorial. She is responsible for communicating with the other authors about progress, submissions of revisions and final approval of proofs.

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