

‘Congenital Heart Disease, Lockdown and me: Global Perspectives of Living through a Pandemic’

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Over the last year children, young people, and adults with congenital heart disease (CHD), their families, health care professionals, organisations and charities supporting them, have faced unprecedented challenges due to the SARS-COV-2 pandemic. In recognition of the impact on health and wellbeing; education and clinical practice, the Congenital Cardiac Nurses Association annual conference on 10th June 2021, in collaboration with the University of Worcester, aimed to explore staff and patient/family perspectives and experiences. The programme included presentations exploring a breadth of digital and clinical innovations, research findings including children’s, young people’s, parents’, siblings’ experiences, and staff experiences of redeployment.

Our first Keynote Speaker, Suzie Hutchinson, CEO of Little Hearts Matter @LHM_UK, explained the fear, isolation and lack of understanding created when a child is diagnosed with half a heart and the additional burden created by the pandemic. For example, whilst the clinical priority for antenatal services was to reduce social contact in line with government recommendations, reducing the number and amending the delivery methods of antenatal and postnatal appointments in the UK (Richens, Wilkinson, Connor 2020), it had a considerable psychological impact. Suzie explained that [some] ‘*mothers received a pre-natal diagnosis on their own, whilst their husband sat in the car outside*’ and discussed the impact of receiving this unexpected news during the pandemic; refer to the March EBN editorial on maternal mental health (Bailey & Gaskin 2021). Furthermore, Suzie described ‘*the emotional covid rollercoaster*’ experienced by families who were frightened due to the early warnings that those with a heart condition were at the highest risk. The initial lack of understanding of SARS-COV-2 and the lack of clarity about the risks, resulted in inconsistent information provision, creating further challenges for parents who needed confidence in their medical team, who did not have answers either. The British Congenital Cardiac Association issued guidance in March 2020 for vulnerable groups and has since provided immunisation guidance in January 2021 (BCCA 2020, 2021)



“Over the last year every life has been affected by Covid- 19. For young people with a cardiac disability, who always feel fragile, the fears have been magnified. Covid-19 has rocked the stability that these young people have strived to create, made them feel more frightened, created a greater understanding that they are disabled. As the world returns to normal it is very clear that for Little Hearts Matter’s young members their normal will always be different”
(Suzie Hutchinson)

Our second keynote speaker, Dr Liza Morton **@drlizamorton**, highlighted the intensified health inequalities for the most vulnerable groups physically, psychologically, economically, and socially; and indicated that measures implemented to protect physical health, such as social isolation, have had a detrimental impact on well-being, particularly in these vulnerable CHD populations (Mesa Vieira *et al*, 2020); increasing fear, anxiety, loneliness, and depressed mood (Carvalho Aguiar Melo, de Sousa Soares 2020). Liza and Calum Calderwood **@CalumCalderwood**, presented results from their study exploring the impact of COVID-19 pandemic on the mental health of adults with CHD and discussed the importance of health care professionals' *'fostering health emotional regulation'* and using *'a growth-focused, psychologically and trauma-informed approach to medicine and public health, recognising the importance of promoting mental health and living well with CHD during the COVID-19 pandemic and beyond'* (www.drlizamorton.com).

Dr Jo Wray **@dr_jowray**, our third keynote speaker, presented the results of a study that explored patients' and carers' perspectives of the impact of COVID-19 on the delivery of care, how changes were communicated and whether health care professionals should do anything differently in any future COVID-19 waves. The findings reflected parental concerns highlighted by Suzie Hutchinson, in terms of how the lack of clarity exacerbated stress and the need for consistent communication (Wray *et al* 2021). An international survey (Cousino *et al* 2020) of 1220 parents, patients and adult carers exploring the impact of COVID-19 on CHD care and emotional wellbeing, found that disruption to care was significant and 75% of participants had high or moderate concern about the risk of the patient with CHD getting COVID-19. Furthermore, the worry about returning for face to face care was significantly higher than worry about the harm resulting from not attending/postponed care.

Our final Keynote speaker, Dr Paul Checchia, **@ChecchiaPaul**, Professor of Pediatrics at Texas Children's Hospital and Baylor College of Medicine proposed that at the beginning of the pandemic, fear became our driving force, and it was fair to be afraid as health care professionals. Whilst there was some early data (Shi, Qin, Shen 2020), this along with the fear, drove the initial impressions about children and families with CHD. Preliminary thoughts were that the heart was key to the severity of Covid-19, and that, therefore, children with CHD were vulnerable, perhaps prompted by the early reports of paediatric multisystem inflammatory syndrome (Ramcharan *et al* 2020; Makiello *et al* 2020; RCPHC 2020). However, Paul presented a summary of papers on PubMed dealing with COVID (total 137,081), as of last week there were 80 in children AND CHD; n=33/80 from 2021, n=6/33 are individual case reports and, therefore, it is difficult to draw meaningful conclusions. The largest case series is of nine children (Haji Esmaeli Memar *et al* 2021). Paul also highlighted the rise in mental health conditions in children and young people as a major theme arising from the pandemic; and last week Children's Hospital of Colorado declared a state of emergency in paediatric mental health (Haefner 2021). Furthermore, Paul urged us to consider the long term sequelae arising from children's sedentary behaviour and lack of physical activity during the pandemic (Dunton *et al* 2020).

The virtual conference met the [University's sustainable development goals](#), whilst creating an opportunity to connect with colleagues globally and to reflect on the varying challenges that individuals, both patients, parents and staff, have faced in the last 12 months. The key theme emerging from the conference, the psychological impact of COVID-19, creates new opportunities for collaborative work, research, learning and practice.

Special thanks to the CCNA organising faculty Dr Rebecca Hill, Di Robertshaw **@diccna**, Eileen Tiernan **@eileentiernan**, Jenny Somer **@somer_jenny**, Jo Fleet and the Technology Enhanced Learning Unit **@UW_TEL** for their support.



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