

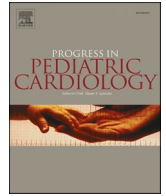


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Original Research

## Strategies to maintain a family-centered care approach in the era of COVID-19: Experiences of a Canadian pediatric cardiology program

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### ABSTRACT

The COVID-19 pandemic has resulted in strict provincial guidelines to prevent its spread. Physical distancing requirements, the postponement of elective pediatric cardiac surgeries and non-invasive cardiac interventions, and hospital visitor restrictions have significantly impacted services provided by our pediatric cardiac program. Rapid modifications to current inpatient and outpatient practices were required to maintain a family-centered care approach. Strategies our team used to maintain a family-centered care approach focused on six key areas including inpatient care, outpatient pediatric cardiology clinics, family meetings, discharge planning and teaching, the connection of inpatient pediatric patients to the outside world, and social support. The majority of our strategies are adaptable to other pediatric cardiology programs and some may prove useful after the pandemic and as restrictions lift. These strategies each have their own limitations and challenges that must be considered when adapting them to other pediatric cardiology programs and continuing their use after the pandemic has resolved.

### 1. Introduction

Family-centered care has been considered the gold standard of care in pediatrics for several decades. Family-centered care is a collaborative partnership that encourages the family's involvement in their child's care [1]. A family-centered care approach commonly includes information sharing, shared decision making, role negotiation, and tailoring of roles to suit individual family members (Fig. 1) [2]. This approach benefits families by enhancing their understanding of their child's medical condition, improving information exchange with the medical team, decreasing their anxiety, and increasing the family's confidence in their child's health care team [3]. Moreover, family-centered care improves patient and family outcomes, enhances overall satisfaction with the care provided, decreases healthcare costs, and leads to better use of health care resources [1].

Similar to other pediatric subspecialties, family-centered care is the standard of care in pediatric cardiology. Due to the advancement of

treatments, surgical procedures, and technology in pediatric cardiology, parents of children with cardiac conditions are continuously navigating a complex health care environment and having to make difficult decisions about their child's medical care. Families who find themselves in this unique position are known for their advocacy and develop specialized knowledge about their child's medical needs that no health care practitioner could learn without their collaboration [4]. Therefore, maintenance of a strong partnership between families and pediatric cardiology healthcare providers is essential to providing quality family-centered care.

### 2. Clinical problem

This partnership between families and health care providers became increasingly more important, on March 11, 2020, when the Director-General of the World Health Organization declared a pandemic related to the COVID-19 virus [5]. In an effort to decrease the spread of

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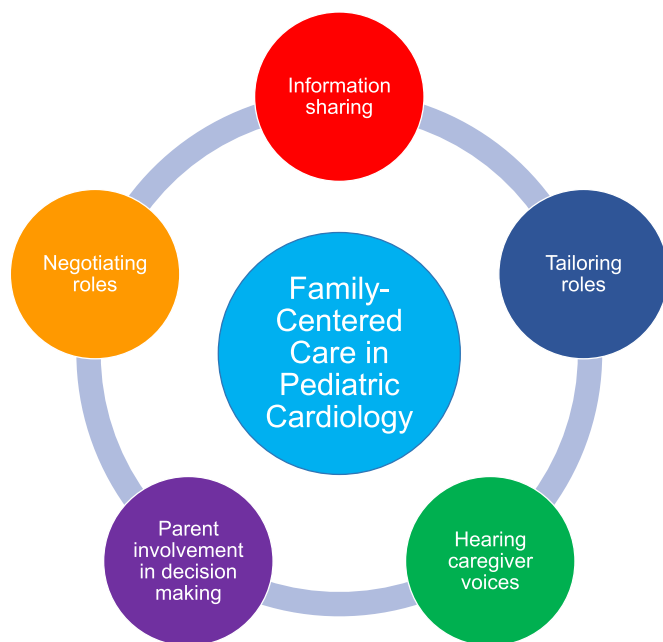
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**Fig. 1.** Themes that are important for achieving a successful Family-Centered Care Approach [2].

Adapted from themes identified in Richard et al. 2018 [2].

COVID-19, the Alberta Government canceled nonurgent surgeries and group therapy sessions and mandated the closure of in-hospital play spaces. Pediatric cardiology patients were allowed only one essential caregiver present with them for outpatient clinic visits and inpatient admissions. Security checkpoints were placed at entrances of the hospital for the screening of staff and visitors. Staff and visitors were expected to maintain a 2-metre distance or to wear a mask when physical distancing was not attainable [6]. These changes created a more challenging environment to provide family-centered care given that physical distancing removes an element of interpersonal connection that is required to build relationships within healthcare.

### 3. Purpose

The COVID-19 pandemic posed unique challenges for our pediatric cardiology program that led to some rapid modifications to our standard approach to family-centered care. These modifications were instituted to decrease the exposure of families and staff to the COVID-19 virus while maintaining a family-centered care approach in our daily care regimes.

The purpose of this article is to share our pediatric cardiology program's approach to maintaining family-centered care while adhering to rapidly changing health care recommendations during the COVID-19 pandemic.

### 4. Impact of COVID-19 on our pediatric cardiology program

At the Stollery Children's Hospital in Edmonton, Alberta, there are over 500 cardiac surgical interventions performed annually, approximately 30–45 cardiac catheterizations performed per month, and over 9000 outpatient visits completed per year [7]. We liaise and coordinate pediatric cardiology care with six other provinces and territories, covering over 4 million square kilometers of Western Canada, making our program unique due to the vast geographical region from which we draw our patient population [7].

Within a 2 month period, in an effort to increase the number of hospital beds available for potential COVID-19 patients, pediatric cardiac surgical cases were reduced by 50%. The number of cardiac catheterizations completed in the first month of the pandemic was reduced

to 50%. All nonurgent electrophysiology procedures were postponed during the first two months of the pandemic. Outpatient pediatric cardiology clinics were limited to in-person clinic visits with children who required urgent assessment or were deemed high risk; otherwise, newly established virtual clinics were used in an effort to reduce the exposure of families and staff to COVID-19.

Despite testing numerous inpatients and clinic patients for the COVID-19 virus, based on viral symptoms, travel history, and contact with individuals with presumed or confirmed COVID-19, none of our pediatric cardiology patients tested positive for COVID-19. Nonetheless, the screening and testing of inpatient and outpatients for COVID-19 has become a part of daily clinic and inpatient care.

Fortunately, there were no barriers to testing inpatients or in-person clinic patients for COVID-19 as testing supplies were made readily available in clinics and the inpatient setting. In the inpatient setting, the on-call virologist could be contacted to approve a test to be put forward for a rapid result when the test was required urgently for diagnosis and treatment of an inpatient. For outpatients identified through screening by phone, testing in Alberta during the initial month of the pandemic focused on individuals and families with COVID-19 symptoms who had recently traveled or who were a known close contact of someone who had tested positive for COVID-19. However, once testing centers were well established and community transmission was identified, testing became readily available to outpatients and their families and could be easily accessed within Alberta. Families could book an appointment for testing initially by phone and later online [6].

### 5. The impact of the COVID-19 pandemic on families of pediatric cardiology patients

Treatment of the family as a whole requires recognizing and addressing additional social and financial stressors faced by the family. At baseline, the families we care for in pediatric cardiology have to deal with the stress of their child having open heart surgery and/or other non-invasive cardiac interventions, possible complications, time away from home and their other children, travel, and time off work. During the pandemic, there were many additional financial and emotional stresses experienced by families of children with cardiac conditions, including family members being laid off or having their work hours decreased, parents having to work from home, and schools and daycares being closed. Childcare was limited due to physical distancing guidelines and parents had to assist their children with remote emergency learning, while often working from home themselves. There was also the added fear for parents of children who are already medically vulnerable of being exposed to COVID-19.

### 6. Strategies for maintaining family-centered care in pediatric cardiology during the pandemic

The strategies our team used to maintain a family-centered care approach focused on six key areas which are outlined in Table 1. These six areas included inpatient care, outpatient pediatric cardiology clinics, discharge planning and teaching, family meetings, the connection of inpatient pediatric patients to the outside world, and social support.

In an effort to limit the risk of exposure of inpatients to COVID-19, inpatient rounds which involved a large multidisciplinary team occurred through the use of Skype for Business [8]. This online modality enabled a secure meeting for the multidisciplinary team while maintaining physical distancing. Parents or guardians joined the rounds by being linked into the meeting by phone when the team was discussing their child. Weekend rounds, heart transplant inpatient rounds, inpatient cardiac catheterization team rounds, and inpatient electrophysiology rounds continued to occur at the bedside due to a smaller number of team members. All healthcare workers were required to wear masks when the minimum physical distancing requirements of 2-metre could not be achieved in patient care environments.

**Table 1**  
Strategies and challenges to modifying care during COVID-19.

Key area	Strategy	Challenges
Inpatient rounds	<ul style="list-style-type: none"> <li>• Skype for Business as a secure online meeting platform [8]</li> <li>• Assessment of the child prior to rounds</li> <li>• Obtained the parent's contact information and explained the format for rounds</li> <li>• Parents were conferenced in by phone to join when rounds were occurring on their child</li> </ul>	<ul style="list-style-type: none"> <li>• Technological issues including poor internet connection</li> <li>• Ensuring confidentiality in shared office space</li> <li>• Background noise in shared offices</li> <li>• Lack of webcams for in-hospital computers preventing a video conference call</li> <li>• Lack of visual cues due to the absence of video conferencing</li> <li>• Communication with parents who require an interpreter or are hearing impaired</li> </ul>
Outpatient clinics	<ul style="list-style-type: none"> <li>• In-person clinic visits for high priority patients based upon triaging</li> <li>• Appointments were spaced as safety allowed</li> <li>• Reduction of daily in-person visits to enforce social distancing in clinic areas</li> <li>• Virtual visits for nonurgent patients based upon triaging</li> <li>• Zoom, Skype, FaceTime, or telephone were used for virtual visits [7–9]</li> <li>• For in-person clinic visits, a second parent was allowed to join by video call</li> <li>• Continuous masking was introduced when the 2 m distance could not be maintained</li> </ul>	<ul style="list-style-type: none"> <li>• Only one parent allowed to accompany the child to outpatient clinic visits, imaging, and tests</li> <li>• Triage patients for virtual vs. in person appointments</li> <li>• Ensuring that family members had the devices and applications for virtual visits</li> <li>• Connection issues with the use of virtual platforms</li> <li>• Ensuring confidentiality during virtual visits</li> </ul>
Discharge teaching and planning	<ul style="list-style-type: none"> <li>• Clustering subspecialty visits</li> <li>• Utilizing virtual visits when feasible</li> <li>• Reducing number of staff involved in follow-up appointments</li> <li>• Allowing for longer hospital stays so children could be discharged directly home to isolate with their families rather than transfer to their referring hospital</li> <li>• Discharge teaching was done with one parent present and the other via video call, or was completed twice to provide in-person teaching for each parent</li> <li>• Teaching about COVID-19, its symptoms and precautions were instituted</li> </ul>	<ul style="list-style-type: none"> <li>• Longer hospital stays put patients at risk for complications</li> <li>• Increased health spending with longer hospital stays</li> <li>• Coordinating appointments with other caregivers proved to be challenging at times</li> <li>• Connection issues during virtual teaching</li> <li>• Ensuring family members had devices and applications for virtual teaching</li> </ul>
Family meetings	<ul style="list-style-type: none"> <li>• Use of secure Zoom online meetings [9]</li> <li>• Families who did not have access to devices were provided with laptops which were cleaned before and after use</li> </ul>	<ul style="list-style-type: none"> <li>• Scheduling a meeting time for multiple team members impacted care teamwork loads</li> <li>• Ensuring family members had devices and software set up for the meetings</li> <li>• Technological issues due to lost connections</li> </ul>
Connecting children to the outside world	<ul style="list-style-type: none"> <li>• Sibling boxes were developed by children, decorated and filled with</li> </ul>	<ul style="list-style-type: none"> <li>• Play therapy being limited to the child's bedside.</li> <li>• Ensuring family and friends had devices and</li> </ul>

**Table 1 (continued)**

Key area	Strategy	Challenges
	<ul style="list-style-type: none"> <li>• notes, drawings, stickers and toys</li> <li>• Virtual platforms such as FaceTime to watch siblings open the gift at home [10]</li> <li>• Video-calling for story time with extended family and so both parents could participate in nighttime routines</li> <li>• Video-calling to play virtual bingo, attend peer support groups, and for educational programming</li> </ul>	<ul style="list-style-type: none"> <li>• applications for virtual connections</li> </ul>
Social support	<ul style="list-style-type: none"> <li>• The ability for parents to contact the pediatric cardiologist/or resident on call was unchanged</li> <li>• Provided up-to-date information regarding COVID prevention, symptoms and recommendations on when to seek testing or medical assistance</li> <li>• Discussed specific considerations related to pediatric cardiac surgery, admissions, and postoperative care</li> <li>• Discussed parental fears related to COVID-19</li> <li>• Social work support continued to be available for all families in person or virtually</li> <li>• Social workers assisted families with their applications for government support and to access emergency funds</li> <li>• Social workers found creative alternative housing for families travelling from other regions</li> </ul>	<ul style="list-style-type: none"> <li>• Local supportive housing for out of town families of children requiring medical care was temporarily closed due to restrictions with regards to communal living</li> <li>• Navigating new government income supports</li> <li>• Family members being laid off or work hours decreased</li> <li>• Family members having to work from home</li> <li>• Daycares being closed and limited childcare options for siblings due to physical distancing guidelines</li> </ul>

In outpatient environments, in-person clinic visits were only conducted if the patient was a higher priority, such as an urgent new referral or a patient with acute changes in their health status. Appointments were spaced out to allow for physical distancing in waiting rooms and where cardiac investigations were being done. Outpatient nurse coordinators ensured that postponed appointments and investigations were tracked so they could be completed after the pandemic restrictions were lifted. Virtual visits were coordinated when visits were less urgent, and the patient's clinical status was generally unchanged and stable. Examples of patients who were deemed excellent candidates for virtual visits were cardiomyopathy screens, patients requiring routine heart rhythm device clinic follow-ups, and stable postoperative patients whose surgery was not recent but required a routine follow-up.

In both inpatient and outpatient settings, only one parent or guardian was allowed to accompany their child at a time. As an alternative, Zoom, Skype for Business, FaceTime, or telephone was used to include the other parent or caregiver in the outpatient appointment or discharge teaching when they could not be present in person [7–9]. When a child's condition was complex and involved multiple subspecialties or transition from intensive care to the ward or the community, family meetings were organized via a secure Zoom online meeting [9]. Laptops with camera capabilities were loaned to families of inpatients who did not have their own device to connect to the online family meeting. This platform enabled the family to see the members of the whole care team as they were providing them with information about their child's

condition and care plan. All of these processes allowed for either parents or guardians to have an equal opportunity to participate, ask questions, and receive necessary teaching with regards to their child's care in an interactive setting that still enabled physical distancing.

Connecting inpatient pediatric patients to the outside world proved to be more challenging as inpatient hospital admissions can be a lonely experience for children. Newly imposed measures, intended as a means to decrease viral spread of COVID-19, further disconnected inpatient children from their family and peer groups. To diminish feelings of isolation faced by inpatients during this time, child life specialists were innovative in their strategies to provide play therapy and help children connect with family and friends who could not visit them during their admission. One innovation was sibling boxes, which were decorated by the hospitalized child and filled with notes, drawings, stickers, and toys. Inpatients then used platforms such as FaceTime to watch their siblings open the gift at home and played virtually with them [10]. Similar video-calling platforms were utilized for children to have story time with grandparents and to allow for participation in nighttime routines by both parents. Video-platforms were also used to support child life programming such as virtual bingo, peer support groups, and educational sessions.

In addition, it was important that our program recognized additional stressors on families, validated their concerns, and made appropriate modifications. Identifying when families were overwhelmed and utilizing the strengths of the family in their child's care was paramount. Social workers were consulted on admission of any child under the pediatric cardiology service and an outpatient social worker was available to help families at clinic visits. During the pandemic, consultation was offered in-person or via virtual means. During these uncertain times, our social workers assisted families with their applications for government support and utilized emergency funds to help pay for medications on discharge. The social workers were also creative in finding alternative affordable temporary housing for families traveling from other regions as the local housing options had been temporarily closed due to restrictions with regards to communal living.

At the program level, cancellations of elective pediatric cardiac surgeries and non-invasive cardiac interventions led to growing waitlists. The pediatric cardiology surgical coordinator, electrophysiology navigator, and cardiac catheterization coordinator worked diligently to reschedule pediatric cardiac surgeries, electrophysiology procedures, and catheterizations according to priority level. They were a consistent point of contact for questions from anxious parents about when their child's surgery, electrophysiology procedure, or cardiac catheterization would be, and the precautions that were in place for children coming to the hospital for scheduled procedures.

Moreover, as a team, we fielded many parent-initiated phone conversations and provided education about COVID-19 prevention, symptoms, and recommendations on when to seek testing or medical assistance. We discussed parental concerns and specific considerations prior to surgery, on admission, during the postoperative phase, at discharge, and during follow-up appointments. In addition, we modified our usual care of patients that normally would have transferred back to their home provincial hospital following surgery instead of being discharged directly home. This modification occurred to prevent separation of families from their hospitalized child. This change was in response to a number of provinces that required parents to self-isolate for 14 days away from their hospitalized child after their child was transferred back to the home provincial hospital. Therefore, our inpatient service allowed for children to remain at our hospital until they were safe to be discharged directly home and self-isolate together with their families.

Overall, in our experience, most families seemed comfortable coming to the hospital for cardiac interventions and to clinic for appointments as they trusted that our program and the hospital were ensuring adequate physical distancing and hygiene measures.

## 7. Limitations of strategies for maintaining family-centered care in pediatric cardiology during the pandemic

Typically, care delivery processes are modified over time, based on program experiences, parent feedback, and evidence. In our pediatric cardiology program, prior to the pandemic, family-centered care practices and care plans were well-established through the help of consistent care providers on the ward. In response to our changing patient needs, we had to transform care delivery "on-the-fly" during the pandemic which included using more virtual technology in our patient care. Our facility provides free WIFI in both inpatient and outpatient settings which enabled the integration of virtual technology as a suitable solution, but the use of additional virtual technology in our patient care had several challenges and limitations which are highlighted in Table 1. These challenges and limitations should be considered when adapting our strategies to other pediatric cardiology programs. Important considerations for implementing virtual platforms in both inpatient and outpatient settings that were discovered through this process are outlined in Table 2. When adapting approaches to family-centered care, themes identified in Fig. 1 should be considered to support families and improve outcomes for both the child and the family [2].

## 8. Using pandemic strategies in future care

Although a rapid shift in traditional patient care procedures occurred, some of the virtual strategies used during the pandemic will likely be permanently integrated as a standard of care in the future. Modalities including telemedicine have proven an effective tool in connecting with patients from vast geographical regions. Telemedicine, or 'virtual visits', will likely be used in greater capacity to provide patient care than it had been prior to the pandemic. Increased use of telemedicine technology will allow our pediatric cardiology program and other pediatric cardiology programs to connect more frequently with patients living remotely. Telemedicine may also enable other centers to access a pediatric specialist's opinion while sharing imaging or video of the patient they are concerned about. This technology has been previously reported to be successful, prior to the pandemic, in the care of single ventricle patients who are at risk of mortality in the first 6 months of life [11]. Parents who cannot attend inpatient rounds and clinics would also benefit from virtual technologies still being provided to them when the pandemic is over. Though these specific modalities have not been employed at our centre previously, it is likely that the virtual strategies trialed by our program during the pandemic will act as a stepping stone towards further integration of virtual methods into the care of this complex population in the future.

## 9. Conclusion

High caliber care is an expectation of both pediatric health care

**Table 2**

Considerations for healthcare teams prior to the implementation of virtual platforms in both inpatient and outpatient pediatric healthcare settings.

Considerations prior to implementation of virtual platforms
<ul style="list-style-type: none"> <li>Utilize hospital-based Wi-Fi available on a secured network</li> <li>Consider using webcams if available for an enriched virtual experience</li> <li>Follow a pre-determined format to ensure each person knows their role and when to participate</li> <li>Understand the needs of families prior to rounds. Utilize language interpreter services on calls when needed</li> <li>Reduce background noise on calls by muting when others are talking</li> <li>Use headphones in shared offices spaces so only team members can hear discussions</li> <li>Contact families in advance of visits to determine if they have devices and applications for virtual visits and to explain the format being used</li> <li>Use a teach-back method with parents and families to determine understanding</li> <li>Use blended delivery, allowing for in-person teaching supplemented with virtual sessions as required</li> </ul>



professionals and the families who receive the care. The modification of care delivery to include a family-centered care approach amid a global pandemic has been an unexpected and challenging feat. Despite the rapid shift in daily care routines, resultant family-centered care strategies that can be embedded into regular care routines have emerged. Concerns regarding how these new restrictions may impact care spurred changes to our care delivery, forcing our pediatric cardiology team to find new and innovative ways that continued to include the valued input of families in their child's care.

This experience has been shared to assist other pediatric cardiology programs in maintaining family-centered care during and after the COVID-19 pandemic. By sharing our approach and key strategies, we aim to encourage further discussions and future research regarding family-centered strategies for care provision during the pandemic, as restrictions lift, and after the pandemic has resolved.

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#### Declaration of competing interest

The authors have no conflicts of interest to disclose.

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