



Perceived Impacts of the COVID-19 Pandemic on Pediatric Care in Canada: A Roundtable Discussion

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Abstract

Like other recipients of health care services, pediatric patients and their families/caregivers have been profoundly impacted by health care shifts and broader societal restrictions associated with the COVID-19 pandemic. An online roundtable discussion was facilitated with 7 pediatric clinicians and investigators of a current study examining the impacts of COVID-19 on pediatric care at multiple Canadian sites. Discussants represented a range of pediatric specialities: developmental disability, mental health, cardiac transplantation, respiratory medicine, hematology, and palliative care. We offer the transcript of the roundtable in which discussants reflected on clinical and programmatic experiences of the pandemic, including perceived impacts on children receiving care and their families, potential opportunities for improved health care delivery, impacts on health care providers, and recommendations as we move toward easing restrictions and pandemic recovery. Discussants convey a range of considerations that may have varying relevance for pediatric specialities in terms of practice and program planning.

Keywords

COVID-19, pandemic, pediatrics, family and patient-centered care, roundtable

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What do we already know about this topic?

Past research has found that pandemic-related shifts result in substantial impacts on pediatric care for children with pre-existing medical conditions and their families.

How does your research contribute to the field?

This roundtable discussion with pediatric specialists highlights experiences in providing care during the COVID-19 pandemic.

What are your research's implications towards theory, practice, and policy?

Participants conveyed numerous practice and program planning considerations for pediatric populations in the

current pandemic, but also for recovery and future pandemic preparedness and response.

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Introduction

The limited pandemic literature addressing pediatric care indicates that children with pre-existing conditions may be at heightened risk for adverse health outcomes as well as care challenges when faced with pandemic restrictions. A Canadian pediatric study examining the 2003 SARS pandemic identified issues such as challenges for staff, surge capacity, communication difficulty and emergency operational challenges.¹ Canadian children treated during the outbreak and their families were profoundly affected by care challenges, separation from family, isolation, stigma and grief.²

Given broader societal and arguably deeper impacts of COVID-19 on Canadian society and regional health care systems compared to SARS, the health, psychological and emotional effects of this current pandemic will likely be pervasive and long-standing, yet to date, remain largely unknown. Like other health care recipients across the lifespan, pediatric patients have been subjected to strict precautions including isolation and social distancing; hospital access restriction; follow-up clinic closure; surgery cancellation; limited or unavailable home-based services; uncertainties associated with infection spread and vulnerability; and gowned, gloved and masked health care providers. These experiences may result in heightened deleterious impacts for children, with additional effects on families and pediatric health care providers. For instance, increased illness acuity and other health and psychosocial challenges may extend from service restrictions.^{3,4}

The limited literature and our collective clinical and pandemic response experiences raise compelling questions about the impact of the COVID-19 pandemic on pediatric patients and their families as well as the delivery of care in this challenging time. To identify experiences of care delivery, systems impact and emerging lessons, a nationally-focused COVID-19 pediatric study funded by the Canadian Institutes for Health Research is underway to examine pediatric practice in a range of clinical specialties.

Study investigators, representing pandemic experience in their respective practice specialties, participated in an online roundtable discussion on May 8, 2020, a peak-time of clinical prevalence and social restrictions in Canada, regarding the impacts of COVID-19 on their practice. Roundtable discussants represented a range of pediatric populations and specialties in 2 Canadian provinces (Alberta and Ontario), and the session was moderated by Dr. David Nicholas of the University of Calgary, study principal investigator. Discussants each hold clinical, leadership and/or research roles across clinical specialties, and are based at several Canadian universities, as follows:

1. *Cardiac Transplantation/Transplant Immunology:* (1) Dr. Lori West, Professor, Canada Research Chair in Cardiac Transplantation, and Director, Canadian Donation and Transplantation Research Program, University of Alberta; (2) Dr. Simon Urschel: Associate Professor, University of Alberta
2. *Respiratory Medicine:* (3) Dr. Sherri Katz, Associate Professor, University of Ottawa
3. *Palliative Care:* (4) Dr. Adam Rapoport, Associate Professor, University of Toronto
4. *Hematology:* (5) Dr. Mark Belletrutti, Associate Professor, University of Alberta
5. *Mental Health:* (6) Dr. Gina Dimitropoulos, Associate Professor, University of Calgary
6. *Developmental Disability:* (7) Dr. Lonnie Zwaigenbaum, Professor, University of Alberta

Ethical Approval and Informed Consent

Roundtable questions were distributed to discussants a week before the roundtable session, and the discussion was audio recorded and transcribed verbatim. Informed consent was obtained prior to study commencement. Institutional research ethics board approval was received from the primary study site (University of Calgary Conjoint Health Research Ethics Board, File #REB20-0367). The following is a transcript of the roundtable, with edits for clarity.

Dr. Nicholas: *Thank you for reflecting on important questions related to pediatric care in the context of the COVID-19 pandemic. Our first question is 'What are key challenges in your area of pediatric practice as a result of the COVID-19 pandemic, and what are their impact on children and families?'*

Dr. Zwaigenbaum: Families that I see are facing numerous challenges, some that are general to the broader pediatric population, and others that may be more specific to autism and other developmental exceptionalities. Certainly, diagnostic assessment and follow-up have been challenging. Disruption in services has profoundly impacted this population. Being out of school, out of usual routines, and not being able to access usual supports and services, including respite or aides coming to the home and not participating in recreational activities, have been difficult. Even if we could see some children in-person, personal protective equipment (PPE) would complicate assessment, creating anxiety and making it hard to judge social behavior. Children with sensory

challenges, including those with autism, might find it especially difficult to wear masks. I think this is a group of children that have particularly been impacted by the pandemic.

Dr. Belletrutti: One of the challenges that I've had to face as a hematologist is that all my diagnostic assessments involve bloodwork. It's difficult when labs aren't open or are at reduced hours, or parents are nervous about going to labs because lab personnel are in full PPE. There's an assumption that everyone has COVID-19, and it can be a really frightening experience for children who are already frightened as they are going to give blood for testing. A challenge for us is continually asking, "which tests can I delay?" A bit more generally, I've found that teenage patients are having a tough time and I think that's probably universal as most of their life is their social circle—friends and high school. Not having that engagement is really affecting them, adding more angst to the angst of being an adolescent. With remote medicine, it's challenging to have confidential conversations because typically parents would be excused, but now I wonder if they are really out of the room or perhaps just down the hall listening.

Dr. Dimitropoulos: A key challenge in the mental health system is that service delivery has dramatically shifted. Many day treatment programs and even inpatient services are rapidly discharging young people home. These changes are particularly difficult for people with significant mental health issues as they manage at home without the structure and professional support they need to maintain whatever gains have been made in their mental health care and/or treatment program. There are some unique challenges in delivering children's services via telehealth. For people with mental health issues, it's hard to assess the young person in their natural environment when meeting over an online platform. When youth struggle with complex mental health issues, it is much easier to conduct assessments and to assess changes in symptoms and observe deterioration when managed face-to-face. Conversely, youth who are struggling with anxiety, obsessive-compulsive disorder, eating disorders or school refusal, in some ways, are doing better or struggling less. Youth with some mental health problems are appreciating not being confronted with what provokes their anxiety. Yet, mental health challenges may emerge when transitioning back from social isolation to "normal" life. I think that's going to be challenging in terms of their worries or anxieties, and I don't know if we have sufficient support or have thought carefully through how we're going to support reintegration. Another challenge associated with mental health is that it is more difficult to assess child maltreatment and intimate partner violence when counseling by telehealth, so

creating safety plans can also be a challenge for both parents and youth.

Dr. Rapoport: One of the greatest challenges has emerged when a child is nearing end-of-life and goals of care start changing. Care is often regimented when goals are to prolong life or cure conditions. But as we start to recognize that a child is nearing death, healthcare providers really try to promote quality of life, relax the rules, and reduce the ways that a patient may feel like a patient by focusing more on the person. That involves bringing families together and concentrating on what matters most to them. We feel that it's important that we bring in these people, but we are mandated not to. For those of us who are parents, could we imagine being told that only 1 parent can be with our dying child up until the last hours or days of life? And key people who also are generally encouraged to be a part of this process such as siblings and friends, are not welcome. This not only is a loss for the dying child, but also for these others who are not able to have these meaningful experiences due to limitations on visitors. We do our best to come up with creative ways to overcome these challenges, like virtual visits, which I think make a positive difference. But that is not the same thing as holding your child's hand and being physically present. I think this is going to have a profound effect on how families grieve because they're not being given this opportunity to be together in the way they would like. I think the pandemic is also having a great impact on the choices that families make at the end of life in terms of location of care. Evidence suggests that most adults want to be home at the end of life. The data doesn't show that in pediatrics: generally, a third want to be at home, a third want to be in the hospital, and a third want to be in a hospice (if available). Even if the child wants to be at home, many families are uncomfortable being in that location. But now, they're having to take into consideration other things that, under different circumstances, they wouldn't have to think about. For instance, if they choose to be in hospital because that's where they're most comfortable and where they feel that they'll get the most support, they have to limit the number of visitors. Some families are choosing to be at home when they would not otherwise do so because they have prioritized being together over their level of comfort with their ability to provide good medical care in the home. As a team, we pride ourselves in giving families choices at the end of life. The research shows that if we can give families the opportunity to make certain personal choices, it has an impact on how they do during that end-of-life period and on into their grieving. I think some of the families are feeling like the choices that we are now giving them are really no choice at all because of the way they have to prioritize certain things.

I also think the pandemic and its impact are affecting our ability to give good medical care. Of course, we're able to still manage symptoms from a distance or virtually, or during limited discreet visits with gowns, gloves, masks, etc.; I think we're doing okay on that level. But in supporting care in the family home, for example, visits are not as frequent as they were. In addition, so much of what we provide is psychosocial support to patients and families, which is not always achieved during planned visits. It often happens in a way that's more organic when speaking with a family, but those "off-the-cuff" visits are not occurring anymore. Visits are now carefully planned and timed for when people can be together, and when people are at least risk—and then, we have to move on. That's impacting families.

Lastly, how families are grieving together after the death of a child has been significantly affected. Many of us have rites and rituals that are part of how we grieve the loss of a loved one. But this is something that currently can't occur in the usual way. Creative solutions are being put into place, but they are not the same, and I believe this will have a profound and long-term impact on how families grieve.

Dr. Katz: In providing care in respiratory medicine, assessments require a physical examination and measurement of oxygen saturations and pulmonary function that can't be achieved in a home environment. While we see patients virtually, continue history taking and provide advice to families, a lot of the key metrics that we typically use to assess patients are not available. This makes delivery of care, including changes in medication or approach to care, very difficult and unnerving. There's a lot of, "let's stay the course" and see how things go rather than a progression of medical care. We also struggle with reduced access to some of the things we would normally use to treat patients; for example, there have been shortages of some types of inhaled medications that have necessitated unexpected changes in medication and the way it is delivered for some of our patients. There is concern that if the new delivery device for a medication is not given with teaching of proper inhalation technique, which is normally reviewed in clinic, the medication may not be as effective. There's certainly a lot more fear among children and families of getting sick and acquiring COVID-19; hence, there is worry about coming into hospital to be assessed. In most instances, we have switched to virtual visits, and encouraged families to come to hospital only when having trouble breathing. But we are finding that children who need this medical attention may not come to the hospital as readily, and prefer to remain in their home environment because they view the hospital as a place where they might acquire the

infection. A recent challenge is that as restrictions are lifted and there is now this discussion about return to school and a more "normal" way of living—whatever that looks like—there are questions and fear among families about health risks when reintegrating into these environments. A challenging conversation encompasses how do we best advise families when there really isn't a precedent or evidence to guide us in terms of best practices.

Dr. Urschel: In cardiac transplantation and pediatric cardiology, a significant challenge has been the reduction in surveillance without in-person follow-up. We require specific testing in terms of echocardiograms, ECGs, catheterizations and MRIs which currently cannot be done as frequently. We've moved to virtual clinics so we can check on patients' clinical and emotional well-being and answer questions, but patients don't get the degree of technical surveillance that they are used to. That leaves some families and care providers uneasy, as they know that biopsies and echocardiographic findings offer additional safety of not missing rejection or other transplant-related concerns. Similarly, accessing bloodwork has presented some challenge because many of the labs are closed. A few labs are effective in drawing blood from children, with some of these labs offering families specific times and having families wait in their cars until their turn. We have also tried to arrange for home blood collections, but this hasn't worked as well. We looked into options such as families self-collecting blood on filter cards, but that could not easily be set-up for transplant-specific needs. Further, there is inherent stress among families, given that some children have required transplantation due to heart disease caused by viral infections. Many families have seemingly experienced a sense of "déjà vu" in re-enacting this critical life event, or an intensified post-traumatic stress reaction arising from their previous transplantation experience.

At the beginning of the pandemic, some families were upset because others were critical about home isolation. For families in which a child has a transplant, being cautious about infections is part of their everyday life. They don't have a problem with adhering to self-isolation rules; rather, I find that parents are uneasy if other people don't want to follow those guidelines.

Dr. West: There's a growing realization that there's no certainty about what normal is going to be. A 'new normal' is likely to emerge as we go along. This adds to the uncertainty that patients and families feel. Among health care providers, there seems to be a dawning acceptance that our practices are not going to be the same as before the pandemic. Components of care that require physical distancing and new ways of working

together, as well as with patients and families, are likely to remain for a long time, perhaps forever.

Dr. Nicholas: *What is needed to better support children and families during this time?*

Dr. Katz: We provide virtual care options which are integrated within home visits. Some of the limitations I described earlier in assessing patients, may be somewhat mitigated because we are able to see the child on video rather than only hear a voice over the phone. Having clear guidelines and greater evidence, which is coming with experience, is helping to better understand the risks to families in undertaking certain activities or coming into hospital. I think that developing the infrastructure to support all of this, is the first thing to tackle. Over time, we will develop innovative ways to mimic in-person assessments remotely and through technology. For example, if we could remotely access a measure of oxygen saturation or a lung function test, a ‘new normal’ clinical assessment is not going to look the same as it did before the pandemic. Finding new ways to navigate care is going to change over time.

Dr. Rapoport: The restrictions that have been put in place in terms of social distancing and visitor restrictions are for the betterment of not only society in general, but also for the families and front-line health care providers. And I think they are the right thing to do. However, these restrictions are creating a lot of challenges for bringing people together at such a difficult time as the end of a child’s life. We considered relaxing some of the restrictions in these situations, but doing so made some people feel uncomfortable and at risk. And I think that’s understandably so; hence, I think that during a pandemic, these rules are put into place for the right reasons. Having said that though, one thing that we can work on as a health care sector and particularly those involved in end-of-life care, is to remember what a family is going through and make sure that we always do what we need to do with the greatest amount of compassion. What I’ve found is that families are pretty receptive to the rules; they understand why they are in place and are okay in going along with them. But I’ve sometimes seen that the rules are unintentionally delivered in such a way that families are left feeling like they are harboring a disease themselves or are the source of the risk. While not done intentionally and indeed these rules are in place across the board, families are sometimes in their ‘own world’ as they’re watching their child’s life slip away. They may not be completely aware of the changes going on around them; hence sometimes, the changes may be viewed as directed at them. Just simple changes in the way that we deliver rules and policies particularly as they’re being changed, can have a profound effect.

We need to ensure that resources are in place during and following the gradual lifting of the restrictions. It’s really important that all health care providers, especially pediatric palliative health care teams, maintain a close connection with families who might be feeling even more isolated than the average Canadian family during this time.

Dr. Dimitropoulos: We need to increase service access and improve communication. Information about the pandemic is constantly changing, as is the way we deliver services. That all can be overwhelming for young people and their families/caregivers. Within our systems, we must recognize that family needs may also be changing. Along with and beyond mental health issues, some families are struggling with social determinants like insufficient finances or food, and housing insecurity. As mental health providers, we need to think broadly about the kind of support that youth with mental health issues and their family may be needing. I also think that we need to consider providing more flexibility in the times available to support families; ‘nine to five’ may not be optimal if 1 is working with families who have children with mental health issues and their children are in the background or if parents are caring for multiple children or aging parents. For families with financial or other challenges, technology may not be a viable option; hence, flexibility is warranted in additionally using the telephone or other methods of communication. And we need to consider how to integrate such support for families who don’t speak the commonly-used language of the region. We must think about how systems can better work together so that the responsibility isn’t on the individual or family, but on us as a system—how can we continue to collaborate across sectors and systems, and support the most vulnerable who may have involvement across multiple systems like child welfare or mental health? Families need us to collaborate effectively to ensure that we are optimally responding to the multitude of needs that young people with mental health issues may have during the pandemic.

Dr. Urschel: We should work on ways to draw blood in a protective environment and access imaging such that it is (and is perceived as) safe for families; hence, is not delayed. Proactive information and specific guidance are needed in navigating shifting information. Uniform pandemic-related guidance and peer recommendations would be helpful. Specific messaging for populations and health issues such as immune-suppression, mental health concerns, etc. is important so patients and families can determine credible guidance in the current vast sea of information.

Dr. Belletrutti: It is important to remind patients that it’s okay to come to the Emergency Department (ED) if needed. That’s been a real challenge; hence we’ve been supporting families by suggesting, “it’s okay, we will

still take care of you as we need to.” We need to let families know that the ED will look a little different because people have to be cautious. And we need to remind families not to minimize their underlying illness even in the pandemic.

Dr. Zwaigenbaum: To better support children with developmental exceptionalities and their families, we need a more flexible range of care models and a deeper “toolbox.” As we have implemented new models including virtual care, it’s been sobering to observe that there are families that might have benefited from this approach all along. For families who have difficulty accessing services due to geographic barriers, it’s been encouraging to see innovation for improving access. It’s remarkable how quickly some of these models have gotten off the ground, but the process has been a bit haphazard. We’re also very focused on addressing the care needs of people who might contract/have contracted COVID-19. We also need a more comprehensive response plan that addresses the health care needs of the broader population. For children with developmental disabilities, such a plan would involve greater communication, co-operation, and coordination across care sectors, including health, education and social services.

Dr. Nicholas: How have pandemic-related challenges affected health care/service providers, and how can they be better supported?

Dr. West: It’s a total readjustment—going from early “panic” mode to a realization of what we are doing now and then to what we will do as we look into the future. I wonder if we’re coming to the realization that all of us have something important to contribute. Because COVID-19 is having such a pervasive effect on all of our lives, we may be making new connections in realizing that everyone adds expertise and contributes to the equation, even if not a front-line virologist working on vaccines. The novel and effective ways we work through this, as well as the various systemic advances, as others have spoken about, will continue to be helpful.

Dr. Katz: With advancement of time in the pandemic, we’re learning new ways of doing things. This is like a giant experiment to figure out what components of virtual care are beneficial to patients. Benefits that emerge from this pandemic may be realizing when it’s appropriate to use one type of care versus another. There is a very steep learning curve in considering how to practice in a different way, resulting in stress and anxiety. There’s worry about whether we are doing the best we can for patients. Are we providing care in a way that’s safe? And how do we ensure that patients continue to do well at home, seek care appropriately, and not get into trouble?

I think that improved supports will come through creating greater infrastructure, ongoing care, and understanding what can and can’t be done virtually.

Dr. Zwaigenbaum: Service providers are facing personal and family challenges related to the pandemic at the same time that they’re on a steep learning curve professionally. Those who work with children and youth with developmental disabilities have been challenged in the way they operate. They are distanced from colleagues on their team, and it’s more difficult to collaborate with educators and other service providers. That whole framework has been lost, and I think that’s been confusing and disempowering, and it places a lot of pressure on service providers who sometimes feel like they provide a lifeline to children and families who are struggling. Psychologists and therapists have faced unique challenges in being re-deployed or retrained to work in other care environments. To better support care providers, we need to anticipate these types of pressures, and be prepared to roll out a plan in a more stepwise and coordinated way.

Dr. Dimitropoulos: Mental health providers have had to rapidly learn how to use telehealth which has been stressful for those who are not used to these applications, and lack experience and expertise in delivering clinical services through technology or phone. Although there are advantages to using telehealth in being able to connect with families in rural communities, there are many challenges. In assessing a new client for mental health issues, it’s really difficult to develop a trusting relationship online or observe non-verbal cues. Depending on the kind of modality used, it may be a lot harder to deliver family therapy or play therapy. It may be particularly challenging to assess how family members are relating to each other through a screen. Mental health providers care deeply about their clients and we’ve been hearing that they are distressed and worried about how their clients are managing amidst heightened stress. When concerned about family violence, mental health providers feel less able to support individuals or families in the ways that they may have previously. And this is all happening as mental health providers themselves are struggling with their own challenges related to the pandemic; many are caring for their own children or aging parents. Some may be worried about their own or family members’ health if they are required to be in hospital or work face-to-face with patients.

But they are a resilient group, with thoughts about how to engage with compassion with each other and be supportive to colleagues. We’re hearing of teams who are organically creating online support groups whereby they’re making themselves more available not just clinically in providing consultation, but also personally in helping one another emotionally.

Dr. Urschel: If health care providers lack guidance about what to convey to families related to the pandemic, families' worries may be heightened, with potentially more inquiries which health care providers may feel insufficiently informed to answer. That places substantial stress on health care providers. There can be tension between personal opinions of health care providers and official guidelines. And there is a difficult balance between protectiveness and not inducing panic. I think we could be more proactive in generating specific recommendations, not only for patients but also for health care providers when receiving inquiries from families.

Dr. Belletrutti: I think there is a place for virtual visits in the future, specifically follow-up after we establish a therapeutic relationship with a patient and family during the first visit. In terms of support for health care providers, I'm concerned about medical students and residents who are somewhat getting *lost in the shuffle* because we have to restrict which patients they can see. We have to think about conserving PPE; hence, we're reducing the number of people that can go into a room and assess patients. Our medical students haven't yet come back to resume their education. I really feel for those students who are at a loss and want to help and learn, but are encountering restrictions that limit their ability to achieve the competencies they need. This may be easier for residents as I see a role for them in virtual care. We may need to encourage colleagues in pediatrics to better integrate learners in virtual visits as educational opportunities for observation and feedback.

Dr. Rapoport: One of the main ways that the COVID-19 outbreak has impacted us is in not being able to provide the best care that we are able to provide; we are settling for the best that we can do under the circumstances. Yet under different circumstances, we know that care could be much better and that is extremely disheartening. I think that we are seeking to accept that this is the best that can be done under the circumstances, but it's hard when you know you could do better. One thing our team has done to better support ourselves is integrate more breaks; colleagues do their time *on* and they go *off*. I find that by the end of the week on service, I feel mentally and emotionally exhausted. But after a week off service, I'm already feeling a little bit better. I have more perspective in recognizing that, "I did the best I could under the circumstances and that's okay." But I need that time and distance to work that out myself. I think the other thing is just listening; I hear teammates struggling with things that they wouldn't normally be struggling with. Although I am limited in the ways that I can make things better, I reach out to them and listen, and where possible, we commiserate together, and there's strength in being able to do that. Knowing that

we're all being challenged by the same issues seemingly makes us feel a little bit better, at least temporarily.

Dr. Nicholas: *What are key lessons emerging from the pandemic and its impact on pediatric care delivery?*

Dr. Katz: I think a key lesson that we've learned is that there is more than 1 way of providing care. Sometimes it takes a crisis to think "outside the box" and see what other forms of care delivery may be available. Another lesson is that a sense of "community" within the medical team is vitally important, which includes communicating with the team that we're all in this together. I actually think in some ways that this experience has created team-building despite it being stressful and hard. It's really brought us together.

Dr. Urschel: An observation across the world is that people are trying to "re-invent the wheel" in believing that "what happened to *them* may not happen to us." One thing to learn is that what has been encountered somewhere else in a pandemic will similarly happen here. At this time in history with extensive global mobility, there is no safe place and no way to fully protect a country from a highly contagious infection short of extremely radical measures. We need to learn from one another and trust knowledge gained by those affected earlier in the pandemic. On a positive note for Canada, within a few days of the pandemic, inter-provincial and international transplant clinicians came together, had weekly calls, sought agreement about how to manage relevant processes, and shared experiences. The provinces mostly followed these recommendations. I think this crisis has demonstrated that people can come together to address pandemic circumstances in a concerted and rapid way.

Dr. Rapoport: I think the lessons are still being learned. As others have said, I think that a lot of people who thought that virtual care or telemedicine just couldn't work for their area, have come to recognize that it can. For a field that strives to be patient and family-centered, I think it can make a huge difference particularly for the complex care population who often have to travel far distances with a lot of equipment to wait in a clinic for a long time. How nice it must be for them to be able to meet their expert health care provider without having to get up early and sit in traffic? I think that's been a real plus and I would like to think that we're going to emerge from this embracing those changes. Yet, there are just some things that technology cannot overcome. It may be a good "second best" and sometimes that's what we have to accept.

Dr. Belletrutti: This experience has reminded us about the importance of the community or small-town

physician who will be the first point of contact for a patient. I'm reminded about how much we rely on them if patients are not willing or able to come to our larger centers. We need to rely on the local expertise and offer support. I think we've always tried to do that, but perhaps that got lost in deference to the specialist. But in moving forward, we need to emphasize the importance of our community partners.

Dr. Zwaigenbaum: One lesson is the importance of partnerships across pediatric and adult health care systems, and coordination in how we plan and allocate resources. We need to continue to consider the broader health care system, and take into account trade-offs in terms of preparedness and limiting the pandemic, but also the risks of withdrawing other types of services. From that perspective, pandemics do not necessarily proceed in a straightforward fashion and probably our strategies in the future need to include some flexibility so that some clinical activities can be quickly ramped up and ramped down to maintain caution and appropriate safety, yet maximally address non-pandemic related care needs.

Dr. Nicholas: *What do you anticipate will be needed to support children and families after the pandemic?*

Dr. Zwaigenbaum: There will be a substantial backlog of assessment and treatment required as well as escalating needs among patients. We require a game plan to "hit the ground running"; hence, we need to immediately start preparing, as there likely will be more needs than ever before. We also can learn from experiences using innovative models such as virtual care during the pandemic, and how these could be beneficial for some children and families longer term.

Dr. Belletrutti: After the pandemic, I think we'll need education for families about why we're conducting in-person visits for some purposes and virtual visits for others. That may help families understand that this shift doesn't mean that their issue is less important than that of others, but rather using technology has helped us see that there are things that we can do virtually rather than in-person.

Dr. Dimitropoulos: Many youth and families/caregivers have missed out on important ceremonies, rituals, special events and occasions, for instance, to celebrate or to grieve the loss of people who have passed away during the pandemic. I think it may be important to be prepared for a "wave" of increased mental health challenges and/or experiences of grief and loss and long waitlists. And we need to be patient with ourselves, given the potential that we as health care providers may have been impacted by post-pandemic trauma or PTSD, and be prepared to provide support around grief and loss.

Dr. Katz: We will likely uncover health challenges that have gone unrecognized or health conditions that have changed during the pandemic. There's going to be a huge amount of "catch-up" to get people back to the level they were at before the pandemic. I think there will be an increase in the care needed by many of our patients.

Dr. Urschel: I think it will be important to provide ongoing information to families about what the "new normal" will be because there will continue to be confusion and worry in society. A positive gain that we'd be advised to take from this experience is to maintain the approach of strong collaboration nationally and internationally. This may help guide us in returning to whatever the new normal will be.

Dr. Rapoport: It's already been touched upon, but the importance of remaining connected with families that experienced the death of a child during the pandemic cannot be understated. It's been said that there's nothing more difficult than losing a child, but I think doing so in the midst of a pandemic takes this to a new level. These families must find ways to grieve without the usual supports. Funerals, memorials, school assemblies, shivas—these are important rituals that help grieving families feel part of a larger community, they bring comfort and send the important message that their child mattered. I'm not sure what the effect will be from the significant alterations in these practices, but I worry about the impact of social distancing on something that is generally helped by the physical presence of others.

Dr. Nicholas: *Thanks to our discussants for their thoughtful insights. Documenting these experiences and perspectives is instructive for this and potential future health crises as well as post-pandemic recovery. We'll no doubt encounter many more challenges in moving through and beyond this pandemic. But on-the-ground reflection on our collective COVID-19 experiences offers considerations for pediatric care and public health programming.*

Summary

The COVID-19 pandemic has been unprecedented in its impacts on health care and other elements of community life and society. Pediatric care to ill or disabled children and their families has been, and continues to be, challenged by tensions in our commitment to child and family-centered care amidst infection control measures. As described by discussants, there are multiple issues in care delivery, resulting in recommendations in the broad domains of communication, patient safety/

Table 1. Identified Issues and Recommendations.

Broad domain	Identified concerns	Suggested recommendations
Communication	<ul style="list-style-type: none"> • Lack of specific information about the pandemic and an onslaught of information that is frequently changing, and often difficult to interpret and evaluate • Lack of and changing information about pandemic response and optimal patient care in the pandemic 	<ul style="list-style-type: none"> • Ensure regularity of targeted information to families and health care providers • Facilitate and strengthen existing partnerships among health care providers; nurture communication across speciality and primary care sectors and across regions to support optimal care • Provide as much transparency as possible in explaining reasons for restrictions
Patient safety and wellness	<ul style="list-style-type: none"> • Vulnerability of patients and families in clinical and community settings • Potential risk to patients/families due to telehealth delivery approaches • Limited access to technical investigations and laboratory surveillance 	<ul style="list-style-type: none"> • Enact consistent messaging to families in optimizing clarity and timeliness of communication; proactively identify and address emerging challenges • Rapidly innovate treatment modification and safety protocols • Develop protocols and environments for safe patient assessment and specimen collection
Workflow/ clinical care	<ul style="list-style-type: none"> • Reduced personnel and resources • Lack of precedent for novel care practices (eg, telehealth) 	<ul style="list-style-type: none"> • Rapidly mobilize coordinated systems to navigate personnel and resource shifts • Create infrastructure and evaluation to support implementation; enable flexibility in care plans
Workplace morale	<ul style="list-style-type: none"> • Strained human resources due to shifts in workplace protocols and restrictions 	<ul style="list-style-type: none"> • Implement feedback channels among teams for pivoting practice and work processes • Ensure health care provider wellness (eg, mutual support opportunities)

wellness, workflow/clinical care, and workplace morale (see Table 1).

The reflections of participating clinicians across multiple patient care areas point to the need for integrated responses at micro (eg, support for patient/family experience), mezzo (eg, program management and staff support), and macro (eg, consistent information to the public) levels. Support to individuals and families as well as health care providers is advised both during and after the pandemic, in seeking to nurture wellness. This seems particularly important in the face of potential pandemic-related trauma or other deleterious impacts resulting from this deep and lingering experience. It is hoped that instructive guidance from *on the ground* stakeholders such as these discussants will assist in the aim of identifying and potentially lessening present or longstanding negative pandemic impacts, and ultimately informing pandemic preparedness in the potential event of future health outbreaks.

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MB - contributed to project design, manuscript review.

GD - contributed to project design, manuscript review.

SK - contributed to project design, manuscript review.

AR - contributed to project design, manuscript review.

SU - contributed to project design, manuscript review.

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References

1. Ratnapalan S, Martimianakis MA, Cohen-Silver JH, et al. Pandemic management in a pediatric hospital. *Clin Pediatr*. 2013;52(4):322-328.
2. Nicholas DB, Koller D. The experience of SARS from a pediatric perspective. *Update, Ontario Lung Association*. 2003;19(3):10.
3. Koller DF, Nicholas DB, Goldie RS, et al. When family-centered care is challenged by infectious disease: pediatric health care delivery during the SARS outbreaks. *Qual Health Res*. 2006;16(1):47-60.
4. Koller D, Nicholas D, Gearing R, et al. Paediatric pandemic planning: children's perspectives and recommendations. *Health Soc Care Community*. 2010;18(4):369-77.