

**Open Access Reflection**

**The other frontline during COVID-19: connecting with patients and families in their homes**

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**Abstract**

COVID-19 has significantly impacted how healthcare is being delivered. In this commentary, we share our clinical experience and perspectives on how technology and virtual connections were quickly adopted and applied to the care of children and youth with developmental disorders.

**Keywords:** COVID-19, Frontline, Family.

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The delivery of healthcare has been significantly impacted by COVID-19. A large proportion of outpatient health visits have been quickly transitioned to varied forms of virtual delivery. Technologies such as ZOOM have provided a platform through which connections can be made between patients and their caregivers. Given lockdowns across many jurisdictions, and the necessity for physical distancing, most connections are happening with patients and healthcare providers logging in from their homes. Consent is needed to move forward with these connections, and our awareness of privacy issues is heightened more than ever before. While we usually think of the frontlines during pandemics as emergency departments or inpatient units, the metaphor of the battleground is also playing out away from hospitals and acute care contexts.

The nature of our clinical practice in developmental paediatrics involves working with children and youth with developmental disorders, often with co-occurring medical or mental health concerns, and their families. Examples include children with autism spectrum disorder and anxiety, or intellectual disability with epilepsy. While some of these children rely on technology for their day to day functioning, others may have limitations affecting their ability to use technology. Utilization of acute care services is also more common among those with developmental disorders, a reality that continues into adulthood (Durbin et al, 2018). Prior to COVID-19, these children and youth frequently had multiple encounters with therapists, educational personnel, and diagnostic-treatment teams. However, many health professionals now working in acute settings report that they have had limited training in how to address the complex issues these populations present (Zwaigenbaum et al, 2016; Wachob & Pesci, 2017). Such issues may include difficulties in communication, significant reliance on adult supports,

behavioural challenges and sensory difficulties. Additionally, parents, caregivers and individuals with developmental difficulties frequently report not feeling heard within such settings (Muskat et al, 2014).

We are aware that the volume of visits to emergency departments has decreased significantly during COVID-19. At our centre, very quickly after the World Health Organization declared the pandemic, we switched to connecting with children, youth and their families via phone or through a provincially-developed and approved virtual conferencing platform called the Ontario Telehealth Network (OTN). Since March 30, 2020, we have been tracking our experience with individual virtual encounters, and our physician group anonymously completed regular surveys to capture factors such as: duration of encounter, ease of connection, who the interaction was with (caregiver, child/youth, or both), ease of consent, physician's comfort level, parent report of helpfulness and any new diagnostic considerations. We did not capture unsuccessful connections, but do plan to explore this further in the future.

Three-quarters of the 130 encounters have been follow-up visits rather than new assessments, and half of all encounters have involved video conferencing platforms. For those families with whom a connection was made, a significant portion of caregivers directly reported finding the interaction helpful, and suggested continuing to use virtual means to connect in the future. As examples of what families liked, children were assessed in the familiar environment of their homes and less time was spent on commuting to an assessment centre, paying for parking and waiting. Physicians reported feeling comfortable during the encounter. Based on family feedback, physicians also have been given the impression that families are finding the interactions useful/helpful.

More frequent ad-hoc opportunities have arisen to see families collaboratively, working alongside other health professional colleagues such as nurses, behavioural consultants and psychologists in a virtual space.

Challenges that stand out most prominently as part of these interactions are a result of technical difficulties. These have included: limited bandwidth and strength of WiFi or data connection; quality of video or sound; digital invitation missed, misplaced, or sent to the wrong email address; variable digital literacy among professionals and parents; and logistical considerations in setting up the virtual appointment and the follow-up required. Other aspects of these experiences that have emerged as areas of consideration included: limitations in completing a full new assessment due to lack of sufficient collateral information (e.g. reports from schools) and in-person interactions; inability to perform a full physical exam; challenges in being able to respond to subtle non-verbal cues; discrepancies in access to technology for some families; variable availability of interpreters; and context distractions (e.g. child having a tantrum, parent supervising other kids or completing chores during the interaction).

It is clear that post-COVID19, we expect we will enter a 'new normal'; a reliance on more distant (virtual) connections with patients and families will increase. Developmental assessment tools, such as the Autism Diagnostic Observation Schedule (ADOS-2), developed to be administered in person, may require certain adaptations, and further study of their psychometric properties will clearly be needed.

Finally, while it is important to consider what we are learning through our present experience, we must ensure that needs of vulnerable and marginalized populations are not minimized as we continue

to specify certain practices, policies and procedures to guide future activities. What we have learned in our context is one example of what is being replicated across the world. This experience should provide an impetus to be more creative in how we trouble-shoot and problem-solve in our day-to-day clinical practices even when COVID-19 is not plaguing the world. While a lot of media attention and literature may be directed towards a certain kind of frontline healthcare worker such as our emergency department or intensive care colleagues, we must not forget all the other frontlines in which patients, families and health professionals are engaging every day.

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