

Where have all the children gone? Reflections on a flowerless “COVID” spring

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While children have been documented as being infected by SARS-CoV-2 (COVID-19), and mortalities have unfortunately been reported in infants as young as a few weeks [1], this age group is generally perceived as being relatively unscathed [2]. Uniquely, the current COVID-19 virus seems to spare children of severe manifestations of the illness while at the same time they can be asymptomatic carriers [3]. However, when dealing with a population of medically fragile, and/or physically challenged children, attempts to provide supportive care to them at the time of COVID-19 pandemic and heightened public health anxiety is an unpredictable variable.

Being in New York City has been particularly challenging for providers, patients and families as the situation is forever changing. Overall the SARS-CoV-2 outbreak has drastically within a period of a few weeks changed the landscape of medical care delivery models in New York City. Healthcare systems are opening adult beds for the acutely ill leading to pediatric hospital bed consolidation along with re-purposing and expansion of the age limit for pediatric admissions. All elective orthopedic and neuro surgeries have been postponed for several months; hence workflow of referral to pediatric acute inpatient rehabilitation was disrupted. Outpatient clinics for children in need of rehabilitation have seen a dramatic loss of volume and are limited to only nonelective and necessary spasticity medication management, Intrathecal Baclofen (ITB) pump refills, and emergent equipment deliveries. Practically all physical therapy (PT), occupational therapy (OT), speech therapy (SpT) and other rehabilitation healthcare professionals are being redeployed in anticipation of COVID-19 influx of adult patients.

With the closure of schools, parents and caregivers are now struggling to provide the same level of education and stimulation to their children with special needs. Many schools are attempting to continue teaching using online programs or applications but what about the children who have visual impairment or who have poor motor skills? While most typically developing children can navigate through lessons independently, special needs children require one-on-one assistance to use online resources. What if both parents are working from home? It can become a struggle trying to balance working from home productively and giving their child the attention they normally require during the school day. Going to school is also a major source of socialization and is sometimes the only peer interaction children with special needs have. Children with autism spectrum disorder learn important social skills at school and thrive when their day is structured. Disruption in their daily routine can cause anxiety, frustration and outbursts that can affect the whole household. Many children have continued progression of skills with school-based PT, OT and SpT and these therapies are also stopped when schools are closed. Some children who are non-verbal or have limited speech use alternative and augmented communication devices that are owned by the school, and they cannot take these devices home which can also add to their frustration. Some households do not have enough computers or tablets for each child to have their own device, which can cause tension amongst siblings. In addition, special needs children often attend summer school, and it is unclear if this will be an option this year and how that will affect the social and developmental gains children have made during the first half of the school year. Furthermore, the risk of group retrans-

mission of SARS-CoV-2 should be anticipated when they do return to school [4].

Emotional, financial and health care issues are increased in the caretakers of such patients which has been well documented in the literature [5]. Almost a quarter of U.S. children under the age of 18 live with one parent and no other adults <https://www.pewforum.org/2019/12/12/appendix-a-methodology-11/>. This number is somewhat higher in those taking care of special needs children [6]. In the USA there are an estimated 16.8 million caring for special needs children less than 18 years old and over 50 percent of these caregivers are caring for their own children. Caretaker burden in families of children with disabilities is stressful [7]. The caregivers demonstrated an overall decrease in their quality of life, therefore these factors may be independent risk factors associated with delay in of medical care following COVID-19 exposure and/or infection.

A review of current internet postings revealed that information to access services is hard to retrieve, even for the "seasoned" professional. A few sites dedicated to this population have been retrieved such as 'Hot Line for Special Needs Children' in the states of North Carolina (888-600-1685) and New Jersey (888-228-1146). No statistics are yet available for increased census at the Agency for Child Services in New York, nor is there identifiable data as to the increase in need for foster care placement and/or virtual Family Court services during this pandemic.

The American College of Emergency Physicians (ACEP) and the American Academy of Pediatrics (AAP), and the CDC – Children and Youth with Special Healthcare Needs in Emergencies [8] developed an Emergency Information Form to help emergency care professionals and healthcare providers give appropriate care for children with special healthcare needs during crisis.

What pragmatic questions have arisen so far for pediatric rehabilitation medicine healthcare practitioners at the time of epidemiologic and public health emergencies?

Who can provide a history if the parent is critically ill?

With robust use of electronic health records, there should be a pre-emptive mechanism or warning alert for medical providers, social workers, and nursing as to who will be responsible should the unfortunate event happen when our children lose their parents or guardians. This Emergency Information form should always be a part of the medical record and should be easily retrievable by Emergency Medi-

cal Services (EMS). It would seem appropriate for parents or legal guardians under the guidance of social workers to develop a duplicate written or secure computer/flash drive download with the child's medical history, medications, allergies, functional status, supportive medical equipment and orthotic needs (including the names of their vendors and pharmacies) available in the home and school locations. This document should include the home health agency contact personnel and their phone numbers. A backup handwritten "Health care passport" with this information may be considered as well.

Who is the "second in command"?

All children should have a health care proxy and ideally living wills if parent and/or guardians are not readily available. The contact information can also be stored in an accessible and secure place.

What about case management services?

Provide parents/caretakers with emergency contact information of physicians and consider a case management model so that one physician does not serve this role for too many children at a time.

How can communication be best established with the healthcare provider?

Congress passed, and the President signed, the \$2 trillion Coronavirus Aid, Relief and Economic Security Act (CARES Act) stimulus package aimed at addressing the coronavirus disease 2019 (COVID-19) pandemic. The CARES Act, the Centers for Medicare and Medicaid Services (CMS) on March 30 released additional waivers further relaxing Medicare coverage and payment rules for telehealth services as well as other Medicare coverage rules. This latest relief further expands healthcare practitioners' ability to reach patients through telehealth, an important tool for addressing patient needs while reducing in-person contact to slow the spread of COVID-19.

Unfortunately, telemedicine is not always available to all pediatric rehabilitation patients due to several issues. We continue to observe difficulties of telemedicine care such as caregiver inability to download an app or lack of access to an appropriate software platform. In addition, some people do not have a phone that is capable of creating a video connection. Some of the medically complex needs cannot be easily addressed with telephone encounter alone and therefore a telehealth visit

should always be with video and in some cases with telemonitoring capabilities. This is critical specifically for subset of children with tracheostomies, ventilators, neuromuscular scoliosis, feeding tubes and congenital heart disease, etc. Many of these children come to clinic via ambulance and are accompanied by nurses in addition to the caregiver. More frequent and technologically advanced telemedicine visits would permit more efficiency in care delivery and allow more time for direct teaching and patient assessment when in-person visits do occur. Furthermore, New York City has a large amount of residents who do not speak English as their first language. It is not easy for them to describe their concerns when details are lost even when using a live phone interpreter.

Although telemedicine is not always available to every patient, it is a significant step in the right direction towards increased access to care. What are the solutions going forward? Work with telecommunication companies to supply parents with low or no cost cell phone usage for emergencies. The caretakers of our patient population may not have the resources to connect to health providers by cell phones or other methods, which invokes the need for more contemporary telemedicine. One should not underestimate the fact that we may not know the precise location of some of our pediatric patients with special needs, especially those who are in the most vulnerable households of recent immigrant families or those who are in a shelters. These children may not have access to healthcare, food, medications, durable medical equipment and other items especially during our current COVID-19 outbreak. Some live in long term care facilities that are also not allowing any visitors. This population is extremely vulnerable and there is anxiety around potential hospitalizations if they get a respiratory infection and in fact may become carriers of SARS-CoV-2. Pediatric rehabilitation services are inherently inter and multidisciplinary. In selected cases there should be a platform for provision of remote telehealth access to PT, OT and SpT as well as psychological/pastoral services during times of major public health crises.

Telemedicine could benefit these patients to continue their therapy when the risk of coming to the hospital or having visitors is too great. Telemedicine could help close the gap so that we can be aware of and start to address our patients' needs.

Public health emergencies such as COVID-19 pandemic can and should teach us a lesson of coordinated universal response in care delivery contingencies. Complexities of care delivery for families and care givers

taking care of children with complex medical, cognitive and behavioral needs should not be understated. COVID-19 public health crises should heighten a dire need for creation of easily accessible "command and control center" at a government, state and city level and the needs of children with special needs and their families should be included into overall planning.

The extent and duration of current and future outbreaks of epidemiologic and other public health emergencies remains unknown but the impact can be mitigated by preparing a list of government and nongovernment agencies that are fine tuned to the special needs children.

There is an overwhelming amount of planning and networking is required for these efforts. Pediatric rehabilitation professionals should be at the table to discuss contingency plans for the vulnerable patients and their families. Hopefully, these resources will not need to be accessed in times of a national tragedy again, but it is important to prepare if they are required.

This pandemic crisis brings about new considerations and challenges regarding how to provide care for this unique population of children with special care needs and their families. Let us renew our dedication to this special group of patients and their families whom we deeply care about, so that we can be proactive and focus on our commitment to the present and future care and the needs of the families in this rapidly changing environment.

The basic question is

"When will we ever learn?" The answer is now.

References

- [1] Hong H, Wang Y, Chung HT, Chen CJ. Clinical characteristics of novel coronavirus disease 2019 (COVID-19) in newborns, infants and children. *Pediatr Neonatol.* 2020; 61: 131-132. doi: 10.1016/j.pedneo.2020.03.001
- [2] Lu X, Zhang L, Du H, Zhang J, Li YY, Qu J, et al. SARS-CoV-2 Infection in Children. *New Engl J Med.* 2020 Mar 18. doi: 10.1056/NEJMc2005073 [Epub ahead of print]
- [3] Rothan HA, Byrareddy SN. The epidemiology and pathogenesis of coronavirus disease (COVID-19) outbreak. *J Autoimmun.* 2020 Feb 26. doi: 10.1016/j.jaut.2020.102433 [Epub ahead of print]
- [4] Kim S, Kim YJ, Peck KR, Jung E. School Opening Delay Effect on Transmission Dynamics of Coronavirus Disease 2019 in Korea: Based on Mathematical Modeling and Simulation Study. *J Korean Med Sci.* 2020 Apr; 35(13): e143. doi: 10.3346/jkms.2020.35.e143
- [5] Anderson D, Dumont S, Jacobs P, Azzaria L. The Personal Costs of Caring for a Child with a Disability: A Review of the Literature. *Public Health Rep.* 2007 Jan-Feb; 122(1): 3-16. doi: 10.1177/003335490712200102

- [6] <https://caregiveraction.org/resources/caregiver-statistics>. 66-67. doi: 10.1097/01.PEP.0000155630.54603.B6
- [7] Flom-Meland C, Mohr P, Mabey R, Chalmers L, Olson M, Shaeffer P. The Quality of Life of Caregivers of Children with Special Needs/Pediatric Physical Therapy: April 2005; 17(1): [8] <https://www.cdc.gov/childrenanddisasters/children-with-special-healthcare-needs.html>.