

How the COVID-19 Pandemic Experience has Affected Pediatric Palliative Care in Mumbai

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Abstract

Introduction: The COVID 19 pandemic has created difficulties for children registered under Children's Palliative Care in Mumbai. 2 hospitals who have started Services last year would like to share their experiences on difficulties faced by Children and their families and unique ways in which solutions were found to help them surmount all odds. **Results:** Some difficulties faced included transport to visit hospitals for doctor's care and essential medications; for those in native place, unavailability of doctors and medications. Difficulty to return home for those from out of Mumbai and vice versa. Unavailability of rations for those who were not original Mumbai residents. **Conclusions:** Unique solutions were found for each family. These are presented in this paper.

Keywords: Care innovated, challenges faced during pandemic, children's palliative care

INTRODUCTION

COVID-19 is here to stay and has affected the entire world. In pediatrics, the pandemic has affected children on a less severe scale, as reports from ICPCN and others (2020) have indicated.^[1] In India also, the incidence of childhood COVID-19 is low, even in hospitals designated for such children, for example, At TNMC and BYL Nair hospital, there were 61 admissions and 2 deaths in 2 months period ending 14th June 2020. At Wadia Children's hospital, some deaths occurred awaiting transfer to COVID facility (Personal communication). Balasubramaniam (2020), among other authors, has published articles that to date, all of them have recovered.^[2] The use of telemedicine for those who cannot attend an outpatient department has been reported for adult patients. It has also been described by pediatricians from different countries. Kressly from the United States and Mahajan from India have shared their experiences.^[3,4]

On March 30, 2020, an 18-year-old female registered with our previous children's palliative care (CPC) project called, saying that her antiretroviral therapy drugs would be over in the next 4 days. Her worry was, "How will I travel to Sion Hospital from Jogeshwari, a Western Suburb of Mumbai, when all the public transport is shut down?" Unfortunately,

she was not allowed to travel in a bus, had to hire an auto at a huge amount and walk to reach the hospital. She was running around the whole day and spent about Rs. 1000. This is how the pandemic is affecting children with life-limiting conditions in the city of Mumbai.

CPC has been working in the field of pediatric palliative care for noncancer conditions since 2010 in Mumbai, when the project through DFID, ICPCN, and IAPC was first started for noncancer children. The first site was Sion Hospital where mainly HIV children were registered. Last year, the Cipla foundation gave us a new chance to start working in the field of noncancer. One such setup has been started at Chhatrapati Shivaji Maharaj Hospital (CSMH) at Kalwa since 2019. Three hundred and thirty children have been recruited since June 2019 to date. Most have neurological disorders – 150

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seizure disorders and 76 children with other neurological conditions. Seven are with major thalassemia who require blood transfusion every month. Twenty-three children with nephrotic syndrome, chronic renal failure, heart diseases, and others need regular monitoring.

Bai Jerbai Wadia Hospital for Children (BJWHC) started a pediatric palliative care unit simultaneously, in collaboration with Cipla Foundation. The unit differs from Kalwa, in that children catered to are mostly inpatients. The pediatric palliative care service is a part of a 300-bedded hospital exclusively dedicated to pediatrics. We are a flying unit that provides inpatient and outpatient services to children with a great variety of life-limiting and life-threatening conditions and their families. Two hundred and seventy-seven children have been recruited from May 2019 to date: one-fifth are treated for cancer, the rest for nonmalignant conditions: congenital malformations, genetic disorders, chronic renal disease, critical illnesses, newborns with hypoxic-ischemic encephalopathy, etc.

WORK DURING THE LOCKDOWN PERIOD

As part of the COVID preparedness, BJWHC set up an isolation ward with dedicated staff of nurses and doctors. Screening, admission, and intensive care protocols were made. COVID-19 positive cases are transferred to COVID hospitals. We familiarized ourselves with the protocols and infection control guidelines and continued our work with due precautions. Clinical rounds have been going on in a similar fashion as before, with our patients in pain and end-of-life taking precedence.

The staff at CSMH were forced to work from home, except the medical officer, who fortunately stays close by to the hospital. A brainstorming meeting led the team to maintain a detailed phone follow-up with every patient to understand and form strategies for all issues arising.

CHALLENGES FACED

At Chhatrapati Shivaji Maharaj Hospital

1. Most children are entitled to free or subsidized medicines. This could not happen due to transport issues and lack of money. Children started developing symptoms
2. Many families went to their native places, without anticipating the challenges of getting medicines or health-care provisions. General practitioners have closed their clinics; hence, the children cannot get help close to home
3. The children who require regular blood transfusion are faced with a shortage of blood; regular donors are unable to come to the centers
4. Children with nephrotic syndrome and chronic renal conditions are not getting the diagnostic tests, and other therapeutic procedures needed due to the transport and financial issues
5. All the workforce in the hospital is focused on the management of COVID-19, many planned procedures, routine tests have been postponed

6. Many caregivers are migrant workers, they are having issues in getting food supplies from the government. They wish to return to their native places, although they are not sure what medical facilities will be available
7. Caregivers feel totally insecure as most of them are daily wage laborers and have lost their jobs. They do not have money to pay the rents
8. They face a host of emotional issues also. They are also afraid to travel to the hospital or native place due to the fear of transmission of COVID-19.

At Bai Jerbai Wadia Hospital for Children

1. The need to respect infection control protocols contradicts the high-touch low-tech aspect of palliative care
2. Patients are having a tough time trying to access medical care. Even before the lockdown, blood donation camps were canceled, leading to serious difficulties to procure blood products and the need to postpone chemotherapies. Intra- and inter-city travel is expensive and hard to find, making it difficult for children with end-stage kidney disease to come for hemodialysis thrice a week
3. Family members of critically ill children are now unable to come together and help parents make difficult decisions for their child
4. Many families suffer from extreme economic hardships under lockdown and are struggling with basic needs such as food and shelter, besides medical treatment. Trusts and nongovernmental organizations (NGOs) helping children with serious medical conditions are not functioning, as they were before the COVID crisis
5. Families in which one spouse is stuck in another state are finding the lack of support difficult to bear. Other parents grieve the loss of their child with no family support. We are no longer been able to support siblings of sick children in the hospital premises
6. Uncertainties of transport and difficulties in procuring necessary equipment have postponed discharge from hospital for many children with chronic conditions, including a number of babies and children remaining ventilator-dependent after weeks or months in a neonatal and pediatric intensive care unit (ICU)
7. Families from outside Mumbai or outside Maharashtra face logistic hardships when they have chosen home for the end of life or to conduct the last rites. No home care services are available during the pandemic
8. Doctors and nurses face transport hardships. They feel for their patients' troubles, for their own families, and worry about their own health. Those working in the isolation ward (which has COVID-19-suspected patients) undergo tremendous stress and have to contend with stigma from neighbors and even other health professionals
9. The minimum number of health professionals comes to the hospital in every department, including ours, due to the transportation issues and risk of infection exposure. Thus, the palliative care team members have to bear more workload, to develop more counseling skills during

shifts without counselor, and have less opportunity for self-care.

NEED-BASED INTERVENTIONS

At Chhatrapati Shivaji Maharaj Hospital

1. The team made 401 calls to establish the first contact telephonically through Whatsapp or regular phone calls to all patients who were contactable
2. Assessment included – medical issues including availability of medicine and food and any other social, psychological, and financial issues
3. One thousand and sixty-five calls were made for follow-ups, coordination with chemist shops, ration providers, etc.
4. Medical care is advised by telemedicine, as most children cannot reach the hospital. Wherever possible, a local General Practitioner has been contacted. In most cases, this has not been possible
5. Streamlining medicinal supply: those able to reach the hospital are advised to come to the hospital and are seen by our doctor, and regular-free medication is given. Initially, this is not easy since the hospital was in a containment zone. Now the hospital is getting geared to focus on the COVID cases
6. For those who cannot afford regular medicines, they are advised to go to the closest chemist shop. The project staff contacts the same and sends an online prescription; payment is made by the project staff, through online modes such as Google Pay, Paytm of BHIM app. Bills and medications are monitored by the staff online. Twenty-six children have been provided financial help for medicines till date
7. Caregivers are being explained all the safety measures to face the challenges during this crisis
8. Families are being provided with psychological and social counseling. The multidimensional team communicates continuously on Whatsapp chat to solve issues simultaneously
9. Liaison with local NGOs and community representatives, doctors groups, social workers networks, nursing associations, psychologist groups, etc., is made daily by the project staff to urge to help them in this crisis. It is remarkable how much local help is made readily available. Around ninety calls were made for networking with other organizations, and majority of them have provided help locally
10. In spite of this, remaining 13 needy families till date have been provided rations from the local shopkeeper by the project staff through online modes such as Google Pay and Paytm of BHIM app
11. Every week 2–3 video meetings take place among the team members where new and innovative ideas emerge on how to help patients.

At Bai Jerbai Wadia Hospital for Children

1. We adapted to the measures of social distancing and minimum contact while keeping masks on at all times.

Nonverbal cues ensure patients and families know, we are giving them our full attention. Our counseling area was shifted to a large and well-ventilated empty ward

2. Symptom management and psychosocial care of children and families are conducted mostly in hospitals but also on the phone. We prioritize patients in pain and needing end-of-life care when we are unable to reach out to all
3. We are now involved in joint counseling sessions for nearly every child in the pediatric ICU, helping parents understand and cope with the additional burdens they face
4. We help organize logistics for home discharge for chronic care or end of life. Liaising with local doctors is very helpful. We guide families whose child died in the hospital to get travel passes and ambulance transport
5. We give families facing financial difficulties the support we can, and liaise with the social service department and with NGOs, for example, St. Jude's Child Care Centers to accommodate families from outside Mumbai and can kids for ration for the needy families
6. We have witnessed examples of mothers in the wards or in the pediatric ICU supporting each other, sharing food, trying to make each other smile even on the hardest of days
7. Our counselors offer their services in the hospital and over the phone through teleconsultation and video consultation if children or families need intensive counseling (postpartum depression, childhood depression, and personality disorder)
8. Our role of supporting overworked and stressed doctors, nurses, and other health-care professionals on a one-to-one basis has become clear to many in the hospital. It is part of our routine hospital duty or over the phone from home
9. Weekly multidisciplinary palliative care team meetings now take place online and provide a space for discussion about patients and families, sharing our feelings, and time for relaxation.

RESULTS

Both hospitals present different scenarios and therefore different challenges. However, their experiences have been clubbed due to the common nature of work caring for children affected by the pandemic and help rendered by our common sponsor. Qualitative achievements are being reported upon.

1. With the financial help to continue the medicines, the episodes of various symptoms, that is, convulsions, for example, were reduced. Liaising with other doctors could find medical relief closer to their homes
2. Telephonic counseling helped families to take rational decisions in child care. Caregivers were helped psychologically as expressed by them; the main benefit expressed was someone available whenever they needed telephonic help. For those who were desperate to return home, again the telephone was a source of rational decision-making in the best interest of the child
3. Provision of ration was helpful to those who could not get it from the government

4. Networking with General Practitioners, NGOs helped in providing contacts for investigations, medications, and other relief for children staying far away from the hospital
5. The telephone line ensures continuity of care for all the children and their families at home or in the hospital
6. It is promoting resilience in all families individually and collectively, as expressed by the caregivers
7. Health-care professionals keep facing with new challenges in providing support, these are solved daily individually or collectively
8. Inpatient psychosocial support to children and families, including symptom management, can continue effectively despite the additional burden on the palliative care team
9. The palliative care team plays a major role in supporting health professionals, who are under greater pressure during the COVID-19 crisis.

Recommendations

As we continue to face increasing difficulties in the wake of the COVID crisis and continuing lockdown, we are firm in our belief that continuity of care must be maintained, and this has led us to continuously adapt while taking care of children and their families. The innovative ideas which have emerged daily while taking care of these children and their families

during the lockdown, is a tribute to the young and innovative multi-professional team workers and the support from the respective hospitals.

The needs of children with life-limiting illnesses should be given priority. They are more vulnerable than COVID-19 positive patients. In the event of developing COVID-19 infection due to the preexisting conditions, their outcomes will be far worse. Otherwise, the world may have to face a non-COVID humanitarian crisis soon.

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Conflicts of interest

There are no conflicts of interest.

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