IAPC Position on Providing Palliative Care for Children in the Time of COVID-19

5.3: The IAPC would like to propose following recommendations for providing palliative care for children with COVID-19 Infection, children with preexisting life limiting conditions and those affected by prevailing COVID-19 pandemic

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I. To adapt the basic principles of paediatric palliative care such as family-centred care, effective pain and symptom management, quality and dignity at end of life, honest communication, shared decision making of treatment goals and provision of grief and bereavement support to the needs of children affected by the COVID-19 pandemic. (Annexure 5.3.1)

II. To integrate palliative care into frontline response to COVID -19 infection by optimal management of distressing symptoms, communication and advanced care planning and by providing psychosocial and spiritual support to children who are seriously ill and dying and to their families. (Annexure 5.3.2)

III. To ensure continuity and provision of paediatric palliative care to children living with existing or newly diagnosed life-limiting conditions. (Annexure 5.3.3).

IV. To protect children from violence, exploitation and abuse in pandemic times and ensure care for children with serious health related suffering of refugee and migrant population and those affected by conflict. (Annexure 5.3.1)

V. To ensure availability and accessibility of life-saving supplies such as medicines including opioids, vaccines, sanitation and education supplies. (Annexure 5.3.1)

Annexure 5.3.1: Impact of COViD-19 Pandemic on Children

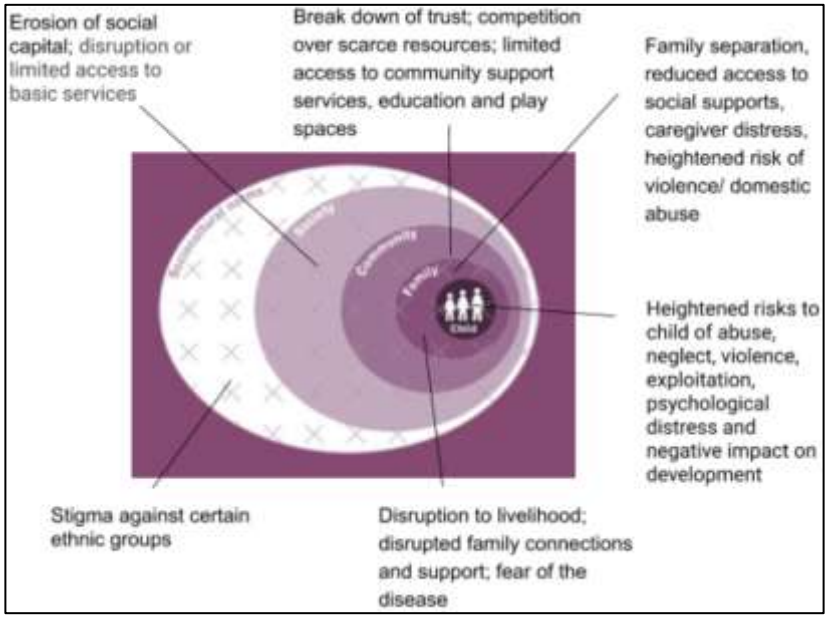
Ensuring the unique needs of Children

- With pre-existing life threatening conditions who are receiving palliative care and/or who would benefit from palliative care

Pediatric palliative care in COVID-19 pandemic addresses the unique needs of children requiring palliative care due to pre-existing life threatening illnesses as well as children who become fatally ill as a result of a pandemic. This also encompasses care of children who are impacted by infection, quarantine or death of the family and the lockdowns disrupting their relationship, school, well-being and the protected environment in which they grow and develop(Picture 1)[1,2]

Quarantine, lock down or infection in the family may affect the basic needs of children such as food, clothing medicines, vaccines, sanitation, education and play. They become the hidden victims to exploitation, violence, abuse[1].

Picture1: Impact of pandemic on children[2]



Advice about Breast Feeding and Vaccination during Pandemic Time

Table 1: Some Frequently Asked Questions Which a Palliative Care Worker Should Know While Dealing with Pediatric Population[3,4]	
Use of Hydroxychlorquine in kids for prophylaxis	Contraindicated in kids below 15 years Asymptomatic household contacts of lab confirmed cases, can be used at the dosage of 400mg BID on day 1 followed by 400mg once a week x 3 weeks
Suppose a child is sent home for quarantine. What are the precautions to be taken?	• Keep patient in a single room with open windows and open door • Limit patient's movement in the house • Shared spaces should be well ventilated and windows should be kept open • Contacts should be in another room or at a distance of 1 meter on a separate bed • One carer allowed per patient • No visitors allowed • Hand hygiene to be followed • Both patient and care giver should wear mask • Do not reuse masks/gloves • Dedicated linen and eating utensils for the patient

What about viral transmission in children?	Transmission occurs via droplets and fomites. Airborne spread can occur with aerosols Vertical transmission unlikely but cannot be ruled out
Breast Feeding	
Suspected COVID-19 Mother	• Direct breast feeding after strict hand and breast hygiene • Triple layer mask for mother while breast feeding • Turn face away from the baby while the mother coughs or sneezes during breast feeding • BCG vaccination 2 weeks follow up ie after isolation period • Telephonic clarification of doubts
Confirmed COVID-19 Mother	• The baby is isolated from the mother till she is cleared of infection • Expressed breast milk (EBM) feeding for the baby • EBM feeding by caretaker of baby using paladai or spoon • OR

	• Direct breast feeding after hand and breast hygiene • Triple layer mask for mother while breast feeding • Turn face away from the baby while the mother coughs or sneezes during breast feeding
Instruction for the discharge of the baby of infected mother	If baby is isolated from mother and 2 samples 48 hour apart RT PCR test negative, baby discharged and looked after by a care taker till mother is fever free, improvement in signs and symptoms and 2 samples 24 hours apart RT PCR test negative.
Recommendation for Immunization during pandemic times	Routine vaccination for all children is recommended Practice all the components of break the chain program • No overcrowding at the venue • Social distancing in the waiting room, vaccination room and observation area • Only one bye stander with the baby • Bye stander should wear 3 layered mask Children from homes where people are in Quarantine period should not

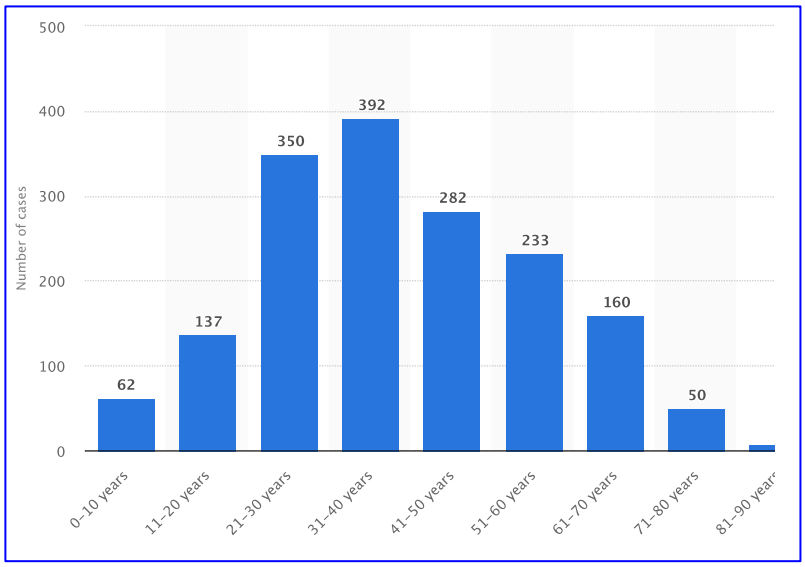
	be immunized till the Quarantine period is over

Annexure 5.3.2: Palliative Care for Children with COVID-19 Infection

COVID Infection in Children

A rapid literature review of 46 studies regarding pediatric and COVID-19 done by Alasdair Munro et.al[5] showed that COVID-19 appeared to have affected children less often and with less severity. Review from China done in 2143 children showed 95% with mild to moderate illness, 5.6% with severe illness (with dyspnoea and hypoxia) and less than 1% with critical illness (with respiratory failure, multi organ dysfunction)[6].To date, deaths in children from COVID-19 are less common with only a handful of cases reported. Early evidence suggested no significant increased risk for children with immunosuppression, but data was insufficient[5]. Compared to many western countries, India seems to have much larger number of younger age group (Picture 2)affected by COVID 19[7]

Picture 2: Age-wise statistics of COVID positive Population, India, April 20, 2020



Children as small as new born are getting infected and dying. There is a risk that due to lack of proper triaging, prognostic uncertainty and due to rapidly declining condition, they may not get good symptom control and end of life care.

Integrating Palliative Care Into Care of Children Infected with COVID -19

Integrating principles of pediatric palliative care to the frontline response to children infected with COVID-19 is highly recommended[8]. Palliative care can help managing distressing symptoms such as severe shortness of breath, secretions and delirium and provide psychosocial and spiritual support for children who are seriously ill or, dying and their families.

Symptom Management for Children with COVID-19

Specific data on supportive ICU care for COVID-19 are lacking, and current recommendations are based on existing evidence from

other viral respiratory infections and general intensive care management. The data on symptoms from adults from a case series of inpatients with confirmed COVID-19 infection at two large acute NHS Hospital Trusts in London, UK shows that the most prevalent symptoms (101) were breathlessness (67), agitation (43), drowsiness (36), pain (23) and delirium (24). According to this study, breathlessness and agitation responded well to opioids and benzodiazepines[9]. The key to good symptom management is proactive assessment and anticipation of the possible symptoms in a child with COVID- 19 infection[10,1 1]

Table 1: General approach to Symptom Management

Table 2: General Approach To Symptom Management And Medication Use[14]
➢ Actively assess for presence of symptom causing discomfort and distress ➢ Assess the severity as well as the frequency and duration of episodes ➢ Correct the correctable ➢ Utilize available symptom management interventions, including non-pharmacologic ➢ Start with minimum dose based on response to prior medications and the goals of care (minimize sedation or maximize symptom improvement) and titrate medication over time ➢ Assess for improvement using tools (when available) , parental reporting and observation of features eg.,

moaning, facial grimacing, spasms, arching, stiffening indicating pain in a nonverbal child

Due to limited availability of workforce, the role of palliative care team will be to provide guidance and to build capacity of frontline workers to adopt palliative care approach to care of critical and terminally ill COVID-19 children.

Table 2- Common Symptoms and Medications used

Table 3: Medications and Pediatric Dosing for the Management of Common Symptoms seen in COVID-1914[10]				
Symptom	**Medication**	**Pediatric Dose**	**Route**	**Interval**
Pain	Paracetamol (Mild pain)	10 – 15 mg/kg, Max 3 gm/day	PO/PR	q4-6h
		10 -15 mg/kg Max 75 mg/kg/day	IV	q4-6h
	Morphine* (or equivalent dose of other opioids) (Severe pain)	0.2-0.3 mg/kg, q 4h, PO or SL	PO/SL	q4h & prn
		0.05-0.1 mg/kg	IV/ Subcut	q4h & prn
Dyspnea	Morphine	0.05-0.1 mg/kg	PO	q3-4h & prn
		0.015-0.03 mg/kg	IV/ Subcut	q3-4h & prn

	Midazolam	0.1–0.2 mg/kg	PO/SL	Titrated to effect
	Lorazepam	0.02-0.05 mg/kg	PO/SL/ IV/ Subcut	Q6h & prn
Delirium	Haloperidol	0.01-0.02 mg/kg For acute agitation- 0.025-0.05 mg/kg May repeat- 0.025 mg/kg in one hour prn	PO	Q8h
	Risperidone	0.25-0.5mg (titrate every 1-2 days, maximum 3 mg total/day)	PO	hs/ divided doses
	Olanzapine	1.25-2.5 (increase weekly if needed, up to 5 mg daily)	PO	hs
	Quetiapine	25 mg (Increase daily by 25 mg/dose, maximum 100-200 mg)	PO	hs Increase to twice daily

	Lorazepam+	0.02-0.05 mg/kg	PO/SL/ IV/ Subcut	q6h
	Clonazepam+	0.005-0.01 mg/kg(0.25-0.5 mg) Increase every 3 days up to 0.05-0.1 mg/kg (max 0.2 mg/kg/day)	PO	q8-12h
Secretions	Injection Glycopyrrolate	0.04-0.05 mg/kg PO q 4-8	PO	q4-8
		0.004-0.005 mg/kg (4-10 mCg/kg)	IV	q3-4
	Atropine eye drops 1%	1-2 drops	SL	q4-6

*Always remember to add laxatives when using opioid medications like morphine. Start with stimulant laxative and may add softener. Some patients may require antiemetic in the initial days. Metoclopramide or haloperidol is the drug of choice as antiemetic in such situation

+ Always add benzodiazepines under the cover of antipsychotic medications in the management of delirium

PO- Per oral
Subcut- Subcutaneous
IV- Intravenous

Communication, Shared Decision Making and Advanced Care Planning

Physicians across specialties find communicating about serious illness to a child challenging. The current COVID-19 pandemic has amplified these challenges, even for those familiar with these conversations. While it is to be hoped that children affected by COVID-19 will not become critical, when a physician does diagnose worsening of condition, advance care planning should be initiated by a prompt discussion between treating physician, parents and child (age appropriate), with one member of palliative care team to facilitate. This would prepare the family adequately and ensure the most comfortable and dignified death which could be provided, in the specific circumstances. These communications can be done face-to-face with personal protective equipment or by virtual means using phone/ Skype/ WhatsApp / teleconferencing/ Face Time etc.

Table 3: Goals of child-family-physician communication

Table 4: The Goals of Child-Family-Physician Communication when a Child is Infected with COVID-19[12]
➢ Advance Care Planning ➢ To share information in a clear, timely and complete manner to empower decision-making ➢ To treat patients and families with dignity and compassion by honoring the patient/family values and providing care

that is in concordance with those values.

- To enhance participation and collaboration of the patients/families with healthcare providers and state/local policies.

Spiritual Care

Spiritual distress is going to be profound for the child and the family with questions like ‘Why me?’, ‘how can this be..? Providing spiritual care will be challenging and conventional face-to-face interaction may not be possible.

Annexure 5.3.3: Palliative Care for Children with Life-Limiting Conditions

Children with pre-existing life limiting conditions are more prone to develop infection and die. They are also vulnerable to lack of care and neglect due to breakdown of family, community and medical support system including supply of essential medications. Experience from Italy’s national lockdown has shown that such children with special needs continued to get sick, could not access adequate care and support and many died[13].

Reorganizing Care to Ensure Pediatric Palliative Care to Children Living with Pre-Existing Life Limiting Conditions

Children with chronic and life limiting conditions such as cancer will continue to need care. The existing palliative care programs need to reorganize their services to changing times.

- Adopting virtual care has become a part of routine practice to ensure continuity of care.
- Vigilance and monitoring to prevent in delay in access to care, ensuring uninterrupted supply of medications and other medical supplies and high quality care coordination are essential part of public health approach to COVID-19 pandemic[13].
- Consider emergency respite for palliative children who are stable but require palliative/end-of-life care when a parent or caregiver becomes unwell.
- Consider admitting children to hospice with significant symptom management needs who are receiving palliative/end-of-life care
- Children who are stable but receiving palliative care at home may not receive home visits, but regular contact through phone/ video will ensure continuity of care.
- After-death care of child and family will require more organized planning around help with handling of dead body, rituals, funeral, death certification and grief and bereavement.

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