5.5 IAPC position on providing home-based palliative care and nursing support for serious COVID-19 patients dying at home and those with cancer and chronic or end-stage organ impairment dying at home whose treatment got limited due to COVID-19 situation

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1) All persons who are dying at home (COVID-19 or Non-COVID-19) will be considered as COVID-19 positive and 'Universal Precautions' and protective measures applied to all.
2) All decisions regarding making a home visit (virtual or physical) to be taken with knowledge and approval of the trained doctor in team. Make a diagnosis of dying and explain this sensitively to the family and carers
3) Always discuss and explain the risks, benefits, and possible likely outcomes of the treatment options with family of patient with COVID 19 or Non-COVID and with patient if appropriate.
4) For documentation Use the Guidance and Care Plan for the Dying document (GCP-D) of 'Project India' of the International Collaborative for Best Care for the Dying Person as outlined in the 'Blue Maple' document and use the home care version attached for ongoing observations. At home do voice recording and detailed documentation later.
5) Emergency palliation protocol for persons dying at home (COVID-19 and Non-COVID-19). If person taking orally, continue oral medication as long as possible. However always initiate and train the family in the use of the Subcutaneous (SC) route ('Family Driver') for giving medication when person not able to swallow and or deteriorating rapidly requiring urgent increase of medication. (Teaching slides and videos on 'Family Driver' available)
6) Adaptations for effective and quick delivery of palliative care and bereavement support.

Annexure 5.5.1: Universal precautions and protective measures

All persons who are dying at home (COVID or Non-COVID) will be considered as COVID 19 positive and 'Universal Precautions' applied to all. Gowns and head gear to be avoided as

communities may respond inappropriately due to fear. Sanitizer, face shields, masks, gloves, aprons should suffice. Make sure, before entering the home, that all family members and carers are also wearing masks and using sanitizer.

Ref e-book (1) pages 53 -55 for additional information on home visits and universal precautions.

ANNEXURE 5.5.2: Planning and making home visit (Physical or virtual)

For a person already under palliative care and being followed by regular, periodic physical or virtual visits and deteriorating, plan a physical home visit if possible.

On referral of a new patient to palliative care team, note necessary details, change to, or make video call if needed. If Patient is dying plan a home visit if possible.

Initial interaction by voice call and change to video call as needed and record these, with permission of caller. This is important for full documentation later.

Always discuss and explain the risks, benefits, and possible likely outcomes of the treatment options with family of patient with COVID-19 or Non-COVID and with patient if appropriate, so that they can express their preferences about the treatment and escalation plans. Also find out if the person has an advance directive or had expressed their wishes earlier to the family. (2)

For patients with pre-existing advanced comorbidities, check with family if any advance directive present including decision of ‘Allowing Natural Death’ (AND). Document this.

Annexure 5.5.3: Diagnosis of dying - International Collaborative for Best Care for the dying Person (3)

Clinical judgement is paramount. The following are suggestive that the person could be dying.

- Profound weakness, bedbound requiring all care
- Drowsy or reduced cognition, semi-conscious or unconscious
- Diminished intake of food only able to take sips of fluids
- No longer able to take oral medication
- No interest in food, drink, or surroundings
- Severe discomfort, distress, and dyspnoea

- Multi-organ failure

ANNEXURE 5.5.4: Documentation

Use the Guidance and Care Plan for the Dying document (GCP-D) (4) of 'Project India' of the International Collaborative for Best Care for the Dying Person as outlined in the 'Blu Maple' Book. (5)

GCP D 2017 Initial assessment Final-1.c

GCP D 2017 Ongoing assessmen

GCP D 2017 Ongoing assessmen

GCP D 2017 Care after Death Final.do

Annexure 5.5.5: Emergency palliation protocol for symptom control. (6) (7)

For patients triaged to supportive end of life care at home based on either

1. Advanced directive / Expressed wish to family

2. Severe adverse prognostic factors and resource allocation

Underlying principles

1. Patients have a right to relief of suffering at the end of life

2. Application of simple protocols can provide relief in most situations

3. This can be a rapidly progressive disease and some patients will need very intensive symptom control urgently

4. Expert consultative back up by palliative care service will be available 24x7

5. Aim to optimise relief, and minimise staff exposure

6. Sensitive and effective communication is a core element of care

Essential Medication and Equipment – see 6.3 Tool Kit /Home care kit (8)

Symptom Management:

Only emergency palliation at home of a dying person by his family is considered here -

Palliation of severe breathlessness(dyspnoea) / Distress (pain) / Agitated Delirium in a rapidly deteriorating situation.

In a 10 ml syringe load: - 2 amps Morphine 15mg/ml x 2 = **2ml** (30mgsmorphine)

- 2 amps Midazolam 5mg/ml x 2 = **2ml** (10mg Midazolam)
-
- 2 amps Ondansetron 4mg x 2 = **4 ml** (8mg Ondansetron)
-
- 2 amps Haloperidol 5mgs x2 = **2ml** (10mgs Haloperico/)

Family taught to give 1ml of this combination 4 hourly at (6.00 am/10.00 am/ 2.00pm/ 6.00pm/10.00pm/ 2.00am). Also in between anytime as needed (break through dose) additional dose for any distress and continue with the regular dose at the set time. **So, the family will have Six regular doses and 4 prn doses for 24 hours. They can come daily to get a loaded syringe or load it themselves if learnt how to do it.**

The following meds may be provided and given SC as needed after consultation with the Team

Inj Dexamethasone 8mg SC daily, Inj Diclofenac (aqueous) 5omg b.d, may be given prn SC for MS pain

For severe anxiety, breathlessness, and Panic Inj Lorazepam 0.5 mg – 1.0 mg SC may be given

For palliative sedation give 15mg Morphine + 10mg Midazolam + dilute to 5ml and give 1ml additional doses every 10-15mts till desired result.

Inj Fentanyl may be given prn for severe pain (incident pain)

Inj Hyoscine Butyl Bromide may be given for colic pains or secretions

Inj Furosemide 20 mg SC for Pulmonary oedema

Inj Phenobarbitone 200 mgs SC prophylactic b.d if possibility of fits

Dulcolax suppository prn

Also see 5.1.9 for management of intractable symptoms.

or symptom management and algorithms please also refer (9)(10)(11)(12)

Also see e-book (1) page 35 for combination of meds and given as SC continuous infusion.

Annexure 5.5.6: Subcutaneous route (SC) 'Family Driver' for symptom control

The 'Family Driver' method of giving subcutaneous SC medications (18)

The SC route is an established route for giving medications in palliative care. This often becomes necessary when the dying person is unable to swallow oral medication. The usual method is by giving a combination of necessary medication in a 10 ml syringe and given as a continuous infusion by a Syringe Driver.

This is not practical in India as it is costly and requires technical expertise. This can be done in a Hospital or Hospice setting but is not practical for home care in India.

So, an alternative method is to take the same combinations in a 10ml syringe and give I ml of the combination SC every 4 hourly and in-between prn. Usually in a 10ml syringe we can have 6 regular doses and 3 – 4 prn doses. There will be a peak and trough effect like the oral immediate release morphine, but since it is within the therapeutic range, it is effective, and the patient is comfortable. It is indeed very cost effective and can be easily taught to the family and get them organized to give the bolus 1ml injections.

We have done this method in the Bangalore Baptist Hospital over the past 24 years with excellent effect and have had no major complication or any incident of abuse or misuse by patient or family. The SC needle can be kept in place for 1-2 weeks and may be re-sited if there is any induration or erythema.

The following documents (13,14,15,16,17,18) are provided as references to support the practice by BBH palliative care service of providing essential medications by subcutaneous route given by family to provide EOLC for dying people at home.

In honour of all the families in the past, present, and future, willing to do this care at home, we call it the **'Family Driver'**. Truly the subcutaneous route must be 'exploited' as the Family driver method is relevant, practical, and cost-effective to keep the person comfortable at home till the last breath.

Annexure 5.5.7: Teaching slides and video for SC administration of medication during Palliative and EOLC at home.

Care of the Dying Person BBH slide pre

Video SC Route: https://drive.google.com/file/d/1tqULHTuKGiBsRWgznFIYzylP6zjHpi9d/view?usp=drive_web

The video shows loading a 5ml syringe for single injections.

For combinations load a 10ml syringe in the same way and instruct family to give 1ml every 4 hours regularly and in between as needed.

Annexure 5.5.8: Adaptations for effective palliative care for dying patients

Few strategies and adaptations are recommended to meet the increasing palliative care needs of the critically ill patients dying at home and needs of coping by support to the family.

1. There is urgent need to scale up capacity of palliative care teams involved in home care to manage the challenging situations of dying people and their families. Perhaps this could be by using the Blue Maple document through ECHO / Zoom platforms.
2. Palliative care teams to become adept at managing the SC route at home by the 'Family driver' method (13,14,15,16,17,18).
3. Explore further ways of empowering Family carers to manage dying persons at home. (19)(20)
4. Palliative care teams to be adept in making difficult conversations and providing Spiritual support as needed.
5. Communities to be encouraged, empowered, and organised to facilitate and provide all necessary support. This could be students, faith communities, housing associations, and corporates. The WHO /IPM 16 hr curriculum for training volunteers (21) can be used and IAPC certification provided. It could also be reduced to an 8hour programme and applied liberally.
6. Palliative care teams to be adept in anticipatory grief support and later bereavement support. Communities can also be involved in this process of befriending.
7. There is need for trained, efficient, and compassionate home health assistants. Networking with agencies who employ marginalised young people, in need of jobs, to be explored.
8. Networking with set-ups who loan equipment eg wheelchairs, walkers, commodes, hospital beds etc by charging a refundable deposit. Eg 'Mercy Drops' set up in Bangalore Baptist Hospital.
9. Networking with undertakers to get effective, safe, and compassionate service. Community volunteers can also support this and be involved. Preparation of the body to be done professionally and minimal handling to be emphasised.
10. Advocacy drive with the Govt of India to Integrate Palliative care into all health care and especially now to urgently integrate early Palliative care into COVID-19 care (22)(23)(24)(25)

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