



PALLIATIVE CARE AND COVID-19 SERIES
BRIEFING NOTES
COMPILATION



Palliative Care and Covid-19 Series – Briefing Notes Compilation

Sponsoring organizations:

International Association for Hospice and Palliative Care (IAHPC)

International Children’s Palliative Care Network (ICPCN)

Palliative Care in Humanitarian Aid Situations and Emergencies network (PALCHASE)

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Introduction

This document collects the twenty-seven original and lightly edited Briefing Notes prepared for the Global Palliative Care and COVID-19 Series developed between April and September 2020 in response to the emergency of the pandemic and its unprecedented effects on patients and palliative care providers around the world. They are addressed to civil society organizations, UN member states, Secretariat staff at the UN Organizations, policymakers, administrators, service recipients, and health care providers. Each Briefing Note provides a snapshot of globally relevant information and guidance on an issue relating to palliative care in the context of the COVID-19 pandemic.

The series was developed jointly by a working group composed by the Executive Directors and Officers of the International Association for Hospice and Palliative Care (Liliana De Lima and Katherine Pettus); the International Children’s Palliative Care Network (Julia Downing); Palliative Care in Humanitarian Aid Situations and Emergencies (Joan Marston); and the Worldwide Hospice Palliative Care Alliance (Stephen Connor and Claire Morris).

Members of the working group identified the topics that were most relevant to policy makers, providers, and patients. In a second step, experts from countries around the world were identified and invited to write the Briefing Notes. One of the coauthors was asked to lead the drafting process and given the opportunity to invite other experts as coauthors.

Briefing Notes were paired with weekly online webinars presented by one or more of the coauthors as well as patients or representatives of affected groups. The Briefing Notes and the webinars were disseminated free of charge through digital platforms. All the individual Briefing Notes and the webinars can be found in the Global Palliative Care website <http://globalpalliativecare.org/covid-19/?show=global-palliative-care-organizations-special-series-on-covid-19-and-palliative-care>.

We prepared this collection recognizing that users could benefit from having all the Briefing Notes in a single document for use in their teaching, research, and practice.

We are indebted to all contributors for accepting our invitation to participate in this collaborative project and hope that you will find this document useful.

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1. How Pandemics Affect Health Systems and Resource Allocation: Impact on Palliative Care

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Issue

Pandemics shock all health systems. Most health system responses to COVID19, including in well-resourced countries, neglected palliative care (PC) in the rush to create rapid mitigation, containment, and disease management strategies. (1) However, PC is critical to alleviating serious health-related suffering (SHS) associated with COVID19 and other health conditions. (2)

Background

The unprecedented scale of the COVID19 pandemic has demanded an urgent worldwide response and has tested the resilience of all health systems. Efforts to control transmission of COVID19 and provide urgent care to infected individuals have focused on minimizing the pandemic driven death toll. Pandemics also exacerbate physical, psychological, social, and spiritual suffering caused by the direct effects of the disease rapidly ravaging communities and countries. This causes ripple effects on system coherency and capacity, which increase the risk of infection of the emerging pathogen for patients with underlying disease conditions. Pandemics often have the greatest impact on low- and middle-income countries (LMICs); many of which have weak health systems and high concentrations of SHS. (1)

Key Facts

- Pandemics dramatically modify health system priorities by redefining the essential or non-essential nature of particular resources, services, regulations, and health security measures.
- PC is chronically under-resourced and lacks appropriate legislative and normative frameworks to guarantee system level integration under pandemic conditions.
- PC training is especially limited in LMICs and core competencies to address the growing needs of patients and their families are lacking.
- The COVID19 pandemic will impose further limitations on essential PC human resources, equipment and medications, facility use (i.e., due to repurposing of PC wards) and financing necessary to deliver essential PC services.
- In the absence of pandemic preparedness plans, strategic guidance on health system capacity, and resource mobilization will likely be devised and designed outside normal health system structures, further fragmenting care.

- PC services designed to alleviate suffering will be de-prioritized in health systems lacking universal health coverage (UHC) schemes.
- Non-pharmaceutical measures such as lockdown/shelter-in-place and quarantine orders to ensure physical distancing, make delivery of PC services, especially home-based and community-based care, more challenging.
- Vulnerable persons with non-COVID life-limiting illnesses will be unable to access necessary prevention, treatment, and PC services.
- End-of-life care is significantly altered, depriving patients with COVID19 and other conditions -- and their families -- of support for advance care planning decisions, the opportunity of a dignified death, and family access to bereavement services, exacerbating complicated grief.
- Pandemics overwhelm information systems by shifting surveillance focus to the emerging pathogen, overshadowing key indicators such as population health and quality of life.

Current Status

- Delivery of and access to PC is decreasing while demand for it is increasing exponentially.
- The WHO Operational Planning Guidelines (3) to support country preparedness and response failed to include PC in strategies for maintaining essential health services. (2)

Recommendations to UN member states and civil society organizations

- Strengthen PC services and integrate into health systems, including with telemedicine, to increase coping capacity and resilience for this and future pandemics, and reduce health related suffering of impacted populations.
- Continue delivering essential healthcare services, including PC, a core component of UHC, (4) to maintain and sustain the health of all, emphasizing the ethical imperatives of equity and non-abandonment.
- Adopt the International Narcotics Control Board (INCB) directive, (5) to maintain uninterrupted access to opioid analgesics and controlled medicines by simplifying export, transport, and delivery procedures. (6)
- Adapt and adopt the cost-effective Essential Package of PC services outlined in the report of the Lancet Commission on Global Access to PC and Pain Relief. (1)ⁱ This will facilitate:
 - Upskilling of health workers with appropriate triaging capability to respond to care within the pandemic context.
 - Adequate access to necessary equipment, and medicines.
- Engage in international collective actions to promote the development and exchange of global public goods to safeguard timely PC and pain relief for life-threatening and life-limiting health conditions and end-of-life care.

ⁱ *The Essential Package has been adapted in Appendix 3 as a component of the WHO Temporary Guidance on Clinical Management of COVID19.*

- Ensure meaningful civil society engagement and public participation to guide priority setting (7) and guarantee prevention, treatment, and PC for all.ⁱ

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2. Response to the COVID19 Pandemic in Low- and Middle-Income Countries

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Issue

Health care systems in resource constrained environments are more vulnerable to pandemics and need to plan and mobilize to minimize serious health related suffering.

Background

- The current COVID19 pandemic has been confined mainly to higher income urban areas vulnerable to transmission due to travel and movement of infected persons.
- New cases and deaths are occurring in Africa, Asia, Latin America, and other low and middle-income countries (LMICs) and are likely to be more deadly.
- As significant segments of the population in LMICs work in the informal sector and depend on daily earnings to survive, societal and work restrictions cause serious financial suffering and exacerbate underlying health issues.
- In many LMICs, palliative care services are only just emerging, and although some countries have developed national strategies, much more still needs to be done to make them fit for purpose in the pandemic.
- Palliative care teams are well suited to partner with existing services delivering care to patients with life limiting illness as well as those affected by COVID19.
- Community based palliative care services that can deliver effective care in the home are in their infancy in many low and-middle income countries.

Key Facts

- Health care policy makers and leaders are unaware of the value of including a palliative care component in the COVID19 responses and lack the human and financial resources to integrate it.
- Palliative care guidelines for assessment, communication and basic symptom management are useful tools. (1, 2)
- Guidelines from well-resourced countries prioritize use of expensive PPE. LMICs are innovating and producing more cost- effective alternatives.

Current Status

- Quality of, and access to primary care services, is generally poor and palliative care teams often have to provide basic primary care (for example, management of diabetes or depression) in addition to conventional Western palliative care.
- Health services in LMICs lack basic resources such as personal protective equipment (PPE); critical care units, equipment for breathing support including ventilators, respirators, bi-level positive airway pressure (bipap); etc.
- Policy makers are ignoring healthcare workers' anxiety about becoming infected at work and then infecting loved ones at home.
- Some palliative care services are being redeployed to other areas of healthcare systems, leaving PC patients without care.
- Community health workers, especially women, have concerns about becoming infected in potentially risky situations, and fear that arriving at homes in PPE to see patients could stigmatize the households they attend.
- Restrictions on in-person communication with loved ones in isolation and distress significantly impact patient care.
- Psychosocial and spiritual care must be culturally respectful.
- Hospitals are being inundated by COVID19 patients, creating a need for community-based delivery of essential care to un-infected existing palliative care patients.
- Healthcare workers and family members providing care for patients in the community lack adequate PPE.
- Restrictions on licensing and transport are exacerbating already inadequate stocks of essential medicines (particularly controlled medicines like opioids) in the majority in LMICs.

Recommendations to UN member states and civil society organizations

- Include palliative care in the national COVID19 response framework.
- Integrate palliative care services into health systems. Form collaborations including governments, palliative care associations, and other relevant stakeholders to develop policies and practices regarding clinical, psychosocial, and spiritual symptom management to support colleagues, patients, and families.
- Utilize palliative care resources to train nonpalliative care health workers in communication, clinical decision making, symptom control and issues surrounding grief and bereavement.
- Train healthcare workers including those delivering palliative care, in protocols on infection control and correct use of PPE, so they can safely continue providing home based palliative care to patients without fear of spreading the virus or becoming infected themselves.
- Empower and support community health workers, especially those already trained in palliative care, to safely support affected patients and families.
- Improve access to internationally controlled essential medicines (ICEMs); including opioids, for treatment of breathlessness and other symptoms.
- Provide for practical needs including food and medicine delivery, transportation & regular communication to alleviate loneliness.

- Ensure continuity of concern for quality of life of patients under care and treatment regimens and consider how psychosocial and spiritual concerns can be incorporated into care plans.
- Promote advance care planning at the population level and support community health workers,

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3. The COVID19 Pandemic: Palliative Care and Human Rights

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Issue

Although palliative care is recognized as a component of the right to the highest attainable standard of physical and mental health, healthcare providers, governments, and patients face significant challenges to access that have been amplified by the COVID19 pandemic.

Background

Even in an emergency, the right to health continues to impose legal obligations on governments that are parties to treaties such as the International Covenant on Economic, Social and Cultural Rights. Measures that limit enjoyment of the right are not ruled out but should be enacted after “the most careful consideration of all alternatives” and must be “duly justified.”⁽¹⁾ The COVID19 pandemic and related infection control measures create major challenges for enjoyment of the right to palliative care as a component of the right to the highest standard of physical and mental health, including:

- Significant new palliative care need: many patients with severe COVID19 disease and their families will need palliative care. Patients will face distressing physical symptoms including acute respiratory distress and they and families encounter major psychosocial impacts because of the risk of death and the separation of patients from families upon hospitalization. Children who have lost parents and grandparents will need psychosocial and spiritual support.
- Major challenges to continuity of palliative care for existing patients: both infection risks and pandemic control measures pose significant challenges to the continuity of care for palliative care patients and their families. Palliative care providers may no longer be able to conduct home visits, and patients may face difficulties accessing outpatient palliative care services or obtaining and filling prescriptions.
- Infection risk for providers and patients: access to personal protection equipment for healthcare providers is a problem in many countries, and community palliative care providers face particular difficulties obtaining appropriate protection. Mobile teams, community health workers and volunteers play a critical role in palliative care provision.
- Increased need for psychosocial and spiritual care: negative mental health impacts of family separations when critical and end of life care are required highlight the importance of psychosocial and spiritual care. Infection control measures further complicate care provision, as providers must limit time with patients, wear full-body protective gear, and must often prevent families from visiting loved-ones.
- Scarcity of resources: inadequately resourced hospitals managing heavy patient loads are triggering the development of rationing and triage plans. Healthcare workers fear having to decide who receives care while patients with chronic or advanced illnesses fear not “qualifying.”

Key Facts

- International human rights law stipulates that governments cannot deny or limit equal access to preventive, curative, or palliative health services. (2)
- The right to health is not an absolute right: states must ensure people can enjoy it to the “maximum of available resources.” (3)
- Access to essential medicines, however, even those that are internationally controlled such as morphine, is a “core obligation” that all states must ensure regardless of income level. (4)
- Human rights norms require states to take appropriate steps to protect healthcare workers from harm. (5)
- The International Convention on the Rights of Persons with Disabilities stipulates that states parties must ‘provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons.’ (6)
- The Inter-American Convention on the Human Rights of Older Persons (2018) stipulates a right to palliative care and symptom relief for older persons. (7)
- Recommendation Rec (2003) 24 of the Committee of Ministers of the Council of Europe, identifies ‘palliative care as... an inalienable element of a citizen’s right to health care.’ (8)
- Human rights experts have stated that de facto denial of access to internationally controlled essential medicines for the relief of severe pain and symptoms can amount to cruel and inhumane treatment. (9)

Recommendations

- Frame all national responses to the COVID19 pandemic within a human rights perspective.
- Ensure the availability, accessibility, affordability and quality of basic palliative care services and essential palliative care medicines on the WHO Model List.
- Provide testing, treatment, and palliation of COVID19 free of charge to protect families from further financial impacts.
- Avoid interfering with existing palliative care services or accommodate them if possible.
- Mitigate negative impacts of infection control restrictions on palliative care services
- Exempt palliative care providers from movement restrictions, modify hospital and hospice visitation policies to facilitate safe visits, and extend morphine and other essential medicine prescriptions for 30 days or more.
- Develop and distribute provider guidance on palliative care for COVID19 in collaboration with UN agencies and palliative care associations.
- Train healthcare workers in basic palliative care techniques including psychosocial and spiritual care.
- Protect provider safety by ensuring, whenever possible, the availability of protective equipment for all health workers, including mobile teams, community health workers and volunteers involved in palliative care, and ensure access to telehealth technologies.
- Ensure transparency and clarity around any rationing of treatment or supplies.

- Although the right to health does not prohibit rationing of treatment in emergencies, it does impose procedural requirements such as transparency and appropriate justification for any such decisions. (10, 11)

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4. Bio-ethical Principles, Practices and Recommendations Relevant to COVID19

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Issue

A risk of the pandemic is that not all patients needing care will receive the proper standard. Moreover, when existing circumstances or escalating demand limit resources, systems may be forced to deny treatment to some patients in order to ensure treatment of others having better prognoses.

Background

The COVID19 pandemic has exposed health system and resource deficits in countries of all income levels. Allocation of scarce medical devices and essential medicines entails hard choices and reconfiguration of existing services based on ethical guidelines to ensure humane and respectful treatment and care for all patients. The pandemic imposes the additional challenges of physical distancing and isolation that can affect both COVID and non-COVID patients and their loved ones. Palliative care is essential to provide physical, psychosocial, and spiritual support for patients, families, and practitioners in the context of the pandemic. According to all WHO member states:

“...palliative care is an ethical responsibility of health systems, and [...] it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial, or spiritual, irrespective of whether the disease or condition can be cured [...] end-of-life care for individuals is among the critical components of palliative care”. (1)

Just and fair rules for allocation of scarce resources such as ventilators, personal protective equipment (PPE) and essential medicines are essential. Many countries will find it especially challenging to locate new human and financial resources for COVID patients while maintaining proper standards of care for patients with other medical needs. Palliative care must be provided to all patients who need it regardless of prognosis and is ethically imperative for those not deemed eligible for life supporting interventions. Since the personnel, medications, and equipment necessary for palliative care may themselves become scarce resources under pandemic conditions, just and fair rules for their allocation must be developed. Such challenges call for high levels of personal, social, and institutional solidarity and integrity

Key Ethical Principles for Optimal Care during the COVID19 Pandemic

- Non-abandonment: No person in need of medical care is ever neglected or abandoned. all who need it have access to palliative care.
- Respect for persons: Protection of patient dignity and human rights includes provision of a private space for the dying and their families.

- **Autonomy:** Autonomy is only restricted for compelling public health reasons.
- **Reciprocity:** Protection of public and provider health is prioritized. appropriate infection control precautions are in place, respected, and enforced.
- **Confidentiality:** Patient confidentiality is maintained in the absence of compelling public health concerns.
- **Whole person care:** Accompaniment, spiritual support and bereavement play key roles alongside intensive care, medical treatment, and symptom control.
- **Justice / Fairness:** Patients with similar health conditions have equal access to treatment and care (including protective measures) without discrimination based on ethnicity, religion, sex, age, disability, socio-economic status, or political affiliation.
- **Rules governing allocation of scarce resources such as ventilators are posted in all institution providing care to COVID19 infected patients. The following principles govern formulation and application of rules:**
 - **Inclusiveness:** the most affected population(s) have input when possible.
 - **Transparency:** rules are easily accessible and understandable.
 - **Accountability:** mechanisms exist so affected persons, including clinicians, can challenge allocation decisions.
 - **Consistency and Responsiveness:** Rules are applied consistently, and notice is given when they are adjusted in response to new considerations.
- **Vulnerable Populations:**
 - The care of patients who are particularly vulnerable due to poverty, homelessness, social isolation, or discrimination may include more or more intense psycho-social services.
 - The care of patients who are particularly vulnerable to infection due to chronic illness or disability, or to their living situation, may call for enhanced protective measures.
 - The care of patients who are minors shall be governed by the principle of “superior interest of the child.” (1)

Current Challenges

- Scarcity of essential health care resources including testing, ventilators, PPE, and medicines.
- Suffering of patients and their loved ones exacerbated by physical distancing and isolation, especially at the end of life when opportunities to say goodbye are limited or non-existent.
- Eroding community trust when lack of treatment options is perceived as patient abandonment.
- Uncertainty and anxiety regarding epidemiology, transmission, course, prognosis, prevention, and treatment of COVID19 relative to other, better understood, disease processes.
- Widespread social and economic breakdown induced by the pandemic.

Recommendations

- Ensure that clinicians and other providers of critical services, especially those who face disproportionate risk in helping others, have proportionally priority access to PPE, testing, treatment, and psycho-social support.
- Consider the appropriateness of any interventions in terms of individual patient need, rather than socio-economic status or identity: only begin an intervention if potential benefits are likely to outweigh potential harms.
- Prioritize patient access to scarce resources according to potential benefit, including to improve quality of life, as well as duration.
- Appoint a committee of unbiased, appropriately trained individuals to allocate scarce resources, and post reader-friendly guidelines in accessible locations
- Provide an appeal process for visitation restrictions.
- Include palliative care pathways in all triage policies.
- • Accept that patients with capacity can refuse interventions, even if these would be beneficial.
- Prioritize advance care planning across the continuum of care.
- Optimize health worker communication with patients and families, using electronic devices and associated resources to mitigate the burdens of quarantine. consider appointing a family support person.
- Support healthcare workers with stress and trauma management

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Further Reading:

WHO Updated Guidance on Clinical Management of COVID19, May 2020.

<https://www.who.int/publications/i/item/clinical-management-of-covid-19>

“Ethical principles for optimum care during the COVID19 pandemic” Chapter 22 p. 47.

<https://www.who.int/publications/i/item/clinical-management-of-covid-19>

5. Global Availability of Internationally Controlled Essential Medicines

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Issue

Urgent need to increase system-wide access to internationally controlled essential medicines (ICEMs) for patient care in response to the COVID19 pandemic.

Background

Health systems require adequate supplies of internationally controlled essential medicines (ICEMs) to manage the pain and symptoms of COVID19 patients, many of whom will also need palliative care. Pre-pandemic estimates of ICEM availability noted that 80% of the world's population, the majority in low- and middle-income countries, lack effective access to ICEMs. Major hospitals in the US and European region are now reporting dangerous shortages and have requested governments to increase procurement. This Briefing Note recommends urgent action to improve access to ICEMs in all healthcare systems for the duration of the current pandemic and beyond.

Key Facts

- Acute respiratory distress syndrome (ARDS) and dyspnea resulting from COVID19 disease may range from mild to critical, creating a distressing sensation of suffocation. Management includes mechanical ventilation, which requires patient sedation with ICEMs such as benzodiazepines (i.e., Diazepam) and opioids. Management of breathlessness in non-ventilated patients with ARDS also requires ICEMs, albeit in lower dosages. (1)
- Section 2 of the 2019 World Health Organization (WHO) Model List of Essential Medicines includes opioid analgesics formulations commonly used for the control of pain and respiratory distress, as well as sedative and anxiolytic substances such as midazolam and diazepam. The Model List (EML) is available electronically at list.essentialmeds.orgⁱ
- The International Narcotics Control Board (INCB); the independent body charged with monitoring government compliance with international drug control conventions, is mandated to support member states to ensure availability of internationally controlled substances for medical and scientific purposes, including special stocks for humanitarian emergencies. (2)

ⁱ Essential medicines should be available within functioning health systems at any time in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford

- Patients who have elected, or have been triaged to palliative care alone, also need ICEMs. Once scarce stocks are also distributed for symptom relief of COVID19 patients those suffering with severe illnesses other than COVID19, will face additional barriers to access.
- Clinicians treating COVID19 patients may be unfamiliar with the use of opioids such as morphine in acute contexts.
- According to the United Nations Special Rapporteur for Torture, “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.

Current Status

- Health care services in high-income countries are running low on ICEMs. recurrent stockouts are already endemic in low- and middle-income countries and will be exacerbated with the double onslaught of intensive care patients requiring mechanical ventilation, sedation, and palliative care, and patients requiring symptom relief.
- WHO and national palliative care associations are reporting increased prices from pandemic driven demand spikes and lockdown stressed supply chains. Lockdowns have restricted land, sea, and air cargo, and created workforce shortages.
- Exportation restrictions in many countries, including in Europe, directly impact the availability and affordability of ICEMs.
- The International Narcotics Control Board is calling on governments to ensure that the international supply chains of ICEMs are not disrupted by measures put in place to counter the COVID19 pandemic and contain further transmission of the virus. The Board has reminded governments that in acute emergencies and when competent national authorities are not functioning, it is possible to utilize simplified control procedures for the export to affected areas even in the absence of the corresponding import authorizations and/or estimates. (2)

Recommendations

- Accelerate clinician training, including online, in the use of opioids and benzodiazepines for COVID19 related symptom control. Training specialist nurses to prescribe and deliver opioids to palliative care patients in all “home” settings (as in Uganda and Rwanda) aligns with WHO calls to invest in nurses in this International Year of the Nurse and Midwife.
- Lift COVID19 related exportation restrictions on ICEMs.
- Increase production of ICEMs to meet the COVID19 driven demand spikes (UN Agencies issue a Joint Statement to member states).
- Identify manufacturers to produce cost effective generic bioequivalent ICEMs for low- and middle-income countries. regional or global pooled procurement mechanisms can use existing funds in global and regional entities such as development banks, collaborating with procurement partners, including humanitarian, to increase regional and global buffer stocks.
- Maintain supply chain operations with adequate protection of warehouse stocks, pre-export inspections, safe transportation for drivers, and functioning customs services.
- In consultation with WHO and UNODC, mandate the formation of multi-stakeholder task forces including healthcare providers and narcotics enforcement personnel to accurately assess population

needs and advise national competent authorities on pandemic level procurement and preparedness. (3,4)

- Review national regulations on access to ICEMs for medical purposes to ensure that they contain exemptions for humanitarian emergencies and leverage exemptions.
- Allow hospital pharmacies to dispense opioids to outpatient palliative care patients.

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6. Recommendations for Symptom Control of Patients with COVID19

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Issue

COVID19 is an acute disease with a clinical presentation of pneumonia and accompanying respiratory insufficiency. Thus, typical symptoms are dyspnoea (breathlessness), cough, weakness, and fever. Other symptoms such as anxiety, panic, restlessness, and delirium have been reported. Patients with rapidly deteriorating respiratory failure and who do not receive intensive care, develop acute respiratory distress syndrome (ARDS) with severe breathlessness, anxiety, and panic, requiring rapid intervention for symptom control.

This briefing note covers the symptomatic treatment of these burdening symptoms (1,2). Other clinical problems such as fever, ventilatory failure, thrombosis or coagulopathies are not covered in this brief.

Symptoms and Recommendations

1. **Dyspnoea:** If dyspnoea persists despite optimal treatment of the acute disease, medical and non-medical measures should be used for symptom control.
 - a. **Non-pharmacological interventions** such as body positioning (leaning forward position, pillow support for arms etc); relaxation or cooling of the face with a cool towel (no hand-held fans to prevent dissemination of the aerosol) may alleviate mild breathlessness. Oxygen or high flow oxygen (with oxygen reservoir) may also relieve breathlessness if intensive care and invasive ventilation are not indicated.
 - b. **Pharmacological treatment:** If breathlessness persists despite treatment of the underlying disease, pharmacological interventions should be implemented including the provision of oral or parenteral opioids. Slow-release opioids with constant drug levels may be used for persisting breathlessness. With acute dyspnoea and rapidly deteriorating patients, rapid dose titration with immediate-release application forms applied regularly and as required is preferred.

Recommended treatment:

i. Opioid-naive patients able to take oral medications:

*Morphine oral	2.5–5 mg 4-hourly	
*Morphine slow release	10–0–10 mg**	(8.00 – 0 – 20.00)
***Lactulose	10–0–0 ml	
Supplement antiemetic if required: Haloperidol 0,5–1 mg at night and up to 2-hourly prn		
+ rescue medication as required, up to once per hour (immediate release opioids. 1/6 of the daily dosage)		
Morphine solution	2.5–5 mg**	(= 2-4 drops Morphine solution 2%)
alternatively, Morphine i.v. short infusion/ s.c.		1–3 mg**
* or alternative opioids /** rapid titration according to symptom intensity /***or alternative laxatives (docusate, macrogol, etc)		

ii. *Patients already on opioids and able to take oral medications:*

- Increase dosage of opioids by 20%
- adapt rescue medication (immediate release opioids, 1/6 of daily dosage)
- rescue medication as required, up to once per hour
- continue constipation prophylaxies (i.e. Macrogol)
Example:
Increase by 20%
*Morphine immediate release 30 mg prn **40 mg prn up to once per hour.
Morphine dosages >240mg/d: change application route to parenteral (1/3 dosage - 10%)
* or alternative opioids / **rapid titration according to symptom intensity

iii. *Patients unable to take oral medications*

Opioid naive patients:	**1 – 2 mg i.v./ s.c. 4-hourly or
	**Morphine 5-10 mg/24 h i.v./ s.c. via infusion pump
Example: 50 mg *Morphine ad 50 ml NaCl 0.9%, concentration 1 mg/ml, **Starting dose 0.4 ml/h	
Patients already on opioids:	
Conversion of previous opioid dosage to continuous parenteral application (i.v. or s.c.)	
Example: 60–30–60 mg Morphine p.o. equivalent to approx. 50 mg i.v./24 h	
50 mg *Morphine ad 50 ml NaCl 0.9%, concentration 1 mg/ml, **starting dose 2 ml/h	
*or alternative opioids / **rapid titration according to symptom intensity	

2. **Cough:** Patients with COVID19 potentially suffer from dry cough, or from productive cough caused by bacterial superinfection.

a. **Non-pharmacological interventions:** Include adequate ambient humidity, oral fluid intake, sucking sour candies, saline gargle or upright positioning of the upper body when sleeping as well as home remedies (i.e., ginger and honey, thyme cough solution).

b. **Pharmacological treatment:**

Morphine 3-5 mg p.o./4 h or continuously s.c./i.v. 5-10 mg/24 h
Noscapin 25–50 mg up to t.i.d.
Patients with productive cough should <u>not</u> receive anti-cough medications during daytime.

3. **Respiratory tract secretions:** Respiratory tract secretions may occur in the final stage of life patients with COVID19. Early provision of anti-secretory medication can prevent the development of secretions in the hypopharynx and trachea. However, already existing secretions will not be diminished. Repeated suction as well as parenteral fluids will increase secretions in dying patients.

Pharmacological treatment

Hyoscinebutylbromide continuously s.c./i.v. 20 mg prn up to once per hour
or
Glycopyrronium continuously s.c./i.v. 0.2 – 0.4 mg 2- 5o 4-hourly

4. **Restlessness and Anxiety:** Breathlessness frequently generates restlessness and anxiety. Patients with acute COVID19 infection, respiratory insufficiency, and the decision to limit invasive ventilation therapy require frequent assessment and rapid treatment of acute and exacerbating breathlessness and anxiety.

a. Pharmacological treatment of anxiety and restlessness in patients with breathlessness, supplementing the opioid medication (example)

Lorazepam 1 mg p.o./s.l. (solution with 2 ml water if necessary) prn, up to once per 30 min
or
Midazolam 2.5-5 mg i.v. short infusion/s.c. prn, up to once per 30 min

b. Pharmacological treatment of refractory anxiety and restlessness in patients with breathlessness

- early change to parenteral application route i.v. (or s.c.) continuously or 4-hourly
- Midazolam-infusion pump (**in combination with morphine**)
- starting dose: Midazolam 10 mg/24 h, titrate to effect

Example → 10 mg Midazolam ad 50 ml NaCl 0.9%, rate 2 ml/h
or → Midazolam 2.5-5 mg short infusion/s.c. 4-hourly

5. **Acute Agitation and Delirium:** Patients with COVID19 infections frequently suffer from agitation or delirium caused by infection, hypoxemia, or isolation. Agitation and delirium require timely interventions. Potential causal factors must be assessed and treated, including pain, constipation, or full bladder.

a. Non-pharmacological interventions include assessment and treatment of potential causal factors, communication, provision of a quiet environment (well-lit and quiet room) and orientation for the patient (information on where and who the patient is, as well as on the actual situation they are in).

b. Pharmacological treatment of agitation and delirium

Predominantly **motor restlessness** (example)
Midazolam 2.5–5 mg i.v. short infusion/s.c. prn, up to once per 30 min
or
Lorazepam 0.5–1 mg s.l./p.o. prn, up to once per 30 min
or
Midazolam continuously i.v. or s.c. 10 mg/24 h
Example → 10 mg Midazolam ad 50 ml NaCl 0.9%, rate 2 ml/h

Hallucinations and confusion
Haloperidol 1-2 mg s.c. prn, up to once per 30 min
or
Haloperidol s.c. continuously 2–5 mg/24 h
Example → 5 mg Haloperidol ad 50 ml NaCl 0.9%, rate 2 ml/h

6. Delivery Routes:

- Manipulations in the nasopharyngeal cavity should be avoided, due to the high virus load in this area.
- Patients with uncontrolled coughing or with secretions, should not receive medications via the oral, transmucosal or intranasal route.

Parenteral application routes should be preferred instead. The continuous application of opioids or midazolam usually requires an infusion pump. If no pump is available, medications can be injected subcutaneously or applied as a short infusion intravenously 4-hourly (see table B for dosages). A subcutaneous needle can be left in place and family caregivers can be trained to provide repeated injections using that needle.

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Disclaimer by authors: These recommendations are for reference and do not supersede clinical judgement. We have attempted to decrease complexity to allow barrier-free use in multiple settings. Evidence supports that appropriate opioid doses do not hasten death when used appropriately. Reassess dosing as child's condition or level of intervention changes.

Disclaimer by IAHPC Press: The information contained in the Briefing Notes on clinical and therapeutic approaches and recommendations should not be relied upon as complete or accurate, nor should it be relied on to suggest a course of treatment for a particular individual. Patients and professionals with health care related questions or concerns are advised to contact experts in the field for clinical guidance.

7. Palliative Care for Cancer Patients in Lower- and Middle-Income Countries

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Issue

Delivery and continuity of palliative care (PC) for patients with cancer in low- and middle-income countries (LMICs) with resource constrained health systems in the context of the COVID19 pandemic. “A pandemic is a cause and powerful amplifier of suffering, through physical illness and death, through stresses and anxieties, and through financial and social instability. Alleviation of that suffering, in all its forms, needs to be a key part of the response”. (1)

Background

Palliative care focuses on the prevention and treatment of serious health related suffering arising from any illness that seriously impacts the quality of life. The core principles of palliative care - providing urgent relief of physical symptoms, offering psychological and spiritual support, and providing compassionate care for both patient and family - become critically important during a pandemic. Providing palliative care (PC) for patients with cancer in the LMIC setting is difficult even under normal circumstances. In most LMICs, palliative care services are not fully integrated into the country’s health care systems, and are often loci of isolated provision, whether delivered by NGOs or by small state-run services limited in both geographical area and clinical reach. (2)

Key Facts

- Recognition of the need for palliative care in humanitarian crises is lacking. (3)
- Cancer patients, and especially those with palliative care needs. require close support and monitoring throughout the pandemic.
- The COVID19 crisis is delaying access to critical care because health systems and scarce resources are stressed staff are reassigned to COVID patients staff have contracted the virus. new policies delay access to critical cancer therapies such as surgery and radiation therapy chemotherapy risks further immunocompromising patients.

Current Status

- Basic equipment and PPE are lacking.
- Accessing essential medicines, including opioids, is challenging.
- Trained human resources are scarce.
- Families are facing financial catastrophe.

Recommendations

- Ensure access to essential medicines (such as opioids) and access to protective equipment.
- Increase use of telemedicine and videoconferencing, ensuring goals of therapy and DNR orders are discussed where appropriate.

- Provide appropriate training and preparation across the health workforce, shifting resources from inpatient to community settings. (4)
- Triage towards most urgent PC cases, reserving hospital attendance or admission reserved for those with more acute needs and severe uncontrolled symptoms like pain, oncological emergencies such as spinal cord compression, and some treatment related emergencies.
- Ensure absolute minimum number of fractions for palliative radiotherapy.
- Minimize risk/benefit ratio for palliative chemotherapy.
- Have more goals of therapy conversations.
- Extend opioid prescriptions to 30 days minimum.
- Acknowledge the importance of spiritual care and provide it where possible.
- Manage those who can stay home at home and minimize travel outside the patient's community.
- Practice self-isolation as much as possible.
- Shift resources into the community – this may include support via video conferencing platforms.
- Provide protocols for symptom management especially pain and shortness of breath (4)
- Support teams from other specialties in managing end of life care and in difficult ethical decision making.
- Ensure PPE use by patients and staff per international guidelines, recognizing that these resources are often limited.
- Consider COVID 19 testing for healthcare workers involved in providing cancer care in order to maintain high standards and protect all parties concerned.4

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8. The Psychological and Social Implications of Physical Isolation for Patients and Families During the Coronavirus Pandemic.

Authors

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Issue

Isolation deprives COVID19 patients in intensive or palliative care, patients suffering in isolation in home settings, and associated family members, of the support and human connection they need to manage the psychological impact of severe or refractory infection, and end of life anxieties. Families deprived of adequate farewells may face complicated bereavement. (1)

Background

- Palliative care providers play a unique role in symptom control and in support for patients experiencing psychological and spiritual suffering, as well as for bereaved family members.
- Although physical and social distancing are the most effective means of preventing community spread, the resulting isolation undermines the essential human need for close connection with others. This loss of human connection is particularly problematic for patients who are seriously ill, hospitalized, or at the end of life in an isolated home setting.
- The reprioritization of the criteria for intensive care unit (ICU) admissions and for other potentially curative or life-preserving treatments in many settings and the simultaneous disconnection of patients from their regular health care providers can produce enormous distress in patients and their families. Those who do receive medical care in hospital often have to manage their anxiety or confusion alone, without the support of their family caregivers or social network
- COVID19 infections that progress rapidly and with ICU admissions, allow little or no time for advance care planning or discussions about goals of care, unlike the gradual progression of noncommunicable disease which allows for early palliative care, with advance care planning, meaning-making, and preparation for the end-of-life.
- Patients nursed in isolation, with minimal contact with their families, are likely to have suboptimal quality of dying and death. Further, in regions such as Sub-Saharan Africa, where large numbers of citizens work abroad, families who have lost loved ones have had no means of returning their bodies or of holding family funeral services. (2)

Key Facts

- Symptom control, particularly of breathlessness and anxiety, and management of delirium, helps isolated patients with severe illness face the end of life without the presence of loved ones. Empathic communication, anxiolytic and sedating medication, and facilitation of digital communication with families and loved ones, including to say goodbye, can help to reduce distress and complicated grief. (3)

- Palliative care can be adapted in the context of infection control measures, to situations where patients are separated from their families, with high physical and psychological symptom burden. It can address the escalating incidence of rapidly progressing disease and death in the ICU setting, including the need for more urgent discussions about goals of care, and the potential for greater bereavement morbidity.
- Consistent and reliable communication of information from government and public health leaders and from health care providers, can enhance the sense of community and provide a greater sense of mastery over a frightening and invisible adversary.

Current Status

- Palliative care, where available, is activated on an emergency basis with severe COVID19 infections in order to assess and implement symptom control measures, to alleviate distress in patient and families, to initiate goals of care discussions, to facilitate virtual communication between patients and families as needed and to provide support to bereaved families, when needed. (4)
- There is limited integration and availability of PC in critical care settings or nursing homes, and the activities of hospice services that do exist for homecare have been severely restricted or shut down.

Recommendations to UN member states and civil society organizations.

- Develop holistic national strategies for COVID19 incorporating prevention, medical, palliative, and psychosocial care and education that dispels myths and stereotypes related to COVID19. (5)
- Integrate emergency palliative care with internal medicine and primary care. discuss goals of care with patients and families, including considerations of intensive care admission, in early stages.
- Ensure availability of anxiolytic and sedating medications for use by appropriately trained practitioners.
- Provide healthcare practitioners with coaching in empathic communication and facilitate digital communication with families and loved ones, including for farewells.
- Request that public health officials and health care practitioners deliver clear and consistent communications about precautionary measures, signs of disease progression, treatment access and financial and caregiver support needed to support patients and families. This is particularly important in impoverished areas where there may be limited access of family members to adequate caregiving, health care services, medication, cellphones and internet access, or ability to remove themselves from violent or abusive environments.
- Provide bereavement support as needed for families, particularly those who faced the sudden loss of a family member without time to prepare or to process their distress, including guilt about not being present at the end of life.

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9. Interprofessional Spiritual Care in the Time of COVID19

Authors

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Issue

Current health contexts are inundated with seriously ill COVID19 patients who are suffering deeply (2) - especially in the context of isolation from family members - and in desperate need of spiritual care.

Background

Palliative care recognises the role of spirituality in the care of patients with serious illness. Many organisations have developed recommendations for the integration of spiritual care in palliative care. Spirituality is defined broadly as a “dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.”³ The practice of interprofessional spiritual care is based on a generalist-specialist model of care: providers address spiritual concerns and work with spiritual care specialists in treating spiritual distress. Studies to support this area of care include association of spiritual distress with quality of life, physical pain, depression, and anxiety. Receiving a diagnosis of COVID19 can raise intense questions regarding one’s mortality, resulting in spiritual distress.

Key Facts

- COVID19 has generated a crisis of spiritual distress in healthcare settings that must prioritise urgent clinical symptom and infection control.
- Spiritual distress includes existential distress, struggles with uncertainty, despair, hopelessness, isolation, feelings of abandonment by God or others, grief, and the need for reconciliation.
- The World Health Organization notes that it is the “ethical duty of all healthcare providers and health settings to alleviate pain and suffering, whether physical, psychosocial or spiritual.”¹
- Appropriately trained clinicians can provide spiritual support to patients and families by taking a spiritual history, listening, practicing compassionate presence, praying, or sharing a sacred moment.

Current Status

- Patients and families are experiencing severe spiritual suffering related to COVID19
- Healthcare providers are distressed by the suffering and dying of their patients and by ethical challenges around limited resources and difficult treatment choices

Recommendations

- Educate healthcare providers in spiritual care through programs such as the Interprofessional Spiritual Care Education Curriculum (ISPEC).⁶
- Clinicians at the bedside should:
 - Complete a basic spiritual inquiry, such as the FICA spiritual history⁷ to assess for spiritual distress in patients and document results in the clinical note.
 - Offer compassionate presence, listening, and connection.
 - Help patients to identify inner spiritual resources and access other spiritual resources
 - Acknowledge grief and sadness.
 - Ensure the dignity of the patient.
 - Include patients' spiritual beliefs and values in goals of care discussion.
 - Refer to spiritual care professionals.
 - Advocate for a peaceful death.
 - Provide respectful care of the body after death according to patients' religious or cultural beliefs.
- Spiritual care professionals can provide spiritual care to patients and families, as well as to healthcare providers, via telehealth. They should:
 - Help staff try to make sense of the suffering they are witnessing.
 - Support providers in the provision of spiritual care to patients.
 - Support patients and families via telehealth.
 - Acknowledge global grief and bereavement.
 - Offer rituals, prayers, and practices that facilitate grief.
 - Facilitate reconciliation and connection.
- Advocate for respectful care of the body after death according to patients' religious or cultural beliefs.
- Facilitate a brief service for family members and healthcare providers.
- Serve on ethics teams.

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10. Grief and Bereavement for Family Members who Can't Visit their Sick Relatives or Attend Funeral Services

Authors

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Issue

COVID19 has interrupted the process of grieving as a social and cultural model due to forced separation from dying loved ones at the end of life and the inability to attend funerals.

Background

As difficult as it is for family members to face their loved one's last hours and days, being present with the dying person can be a central component of separating and bidding farewell in many cultures (Hoy, 2013). Although conceptualization of death differs between and within cultures, societies and families, research confirms the therapeutic value of attending to the dying and culturally specific disposal of the dead through funerals, burial rites, rituals, and memorial gatherings in most cultures (Walter, 2010). The opportunity to attend the funeral after a loved one's death usually helps one face the reality of the loss, particularly when the bereaved has not been present during the dying process. This ritual enables the deceased to offer and receive support from others and acknowledges the significance of the deceased's life in the community as well as in the family. As cultures are dynamic and constantly evolve, so are funeral and bereavement rituals (Hoy, 2013). The current health crisis encourages us to draw upon existing alternative forms of mourning that have indicated positive outcomes.

Current Status

- Family members unable to be at the bedside of their loved one are struggling with extreme sadness, guilt, and a sense of failure knowing the dying individual is alone.
- Grief will likely be more complex and potentially more traumatic when loved ones are dying without the presence of friends and family at the bedside.
- Health workers and care staff are making great efforts to stand as proxy family members and most of these are ill-trained to deal with the spiritual, emotional and communication needs required of being with the dying.
- Delays in receiving updated information on the condition of loved ones due to pressure on the health staff are resulting in public resentment, frustration, and anger with the health system.

Key Facts

- Disbelief or difficulty in accepting a loved one's death is greater when people are unable to be physically present either at time of death or at a funeral service after the death.

- Individuals may feel guilt and remorse about unwittingly infecting the deceased if they were a health worker or a family member who had been unwell.
- Family members are left in a liminal state, having been informed of the death, until they are advised of the decision regarding disposal of the body of their loved one.
- Mass graves as seen in New York City, for example, will produce extra bereavement reactions and concerns.
- The lack of compassionate physical touch around the time of death, as well as afterward, creates additional loss for the bereaved.
- Social networks are crucial in managing bereavement where deep connections can form and grow and continue to bind us together.
- Grief will be more complicated when family members and significant others grieve without their usual support network and traditional rituals surrounding the death.

Options

- Whenever possible, the use of phone calls, messages and video links via health workers should be used in hospitals. This helps the bereaved feel they did all they could in the circumstances. Tech support and in-hospital communications devices should be available for family use.
- However, COVID19 deaths often preclude the end-of-life conversations that can be so significant to patients and survivors, and this combined with the separations often preceding the hospitalization or even death at home, set the stage for traumatic bereavement, and this will be challenging for providers who work with the survivors of COVID19 deaths.
- Whenever possible bereaved individuals should be encouraged to participate in individual and group support services. This enables them to maintain a connection to the deceased.

Recommendations

- Facilitate communication between patient and family members during the dying process whenever and as far as possible.
- Encourage families to work with funeral agencies to use virtual options and social media to foster maximum possible social support for families (Nansen, Kohn, van Ryan, & Gibbs, 2017).
- Ensure that bereaved persons can access social networks through whatever means possible in the current circumstances.
- Provide a resource list of bereavement counselors for bereaved families for support, education, and information about expected course of grief.
- Provide bereaved individuals with opportunities to feel safe to express their concerns, questions, and feelings about their loss (Worden, 2018).
- Ensure bereavement support (online initially) is as widely available as possible by experienced practitioners.

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11. How People with Pre-Existing Palliative Care Needs are Affected by the COVID19 Pandemic

Authors

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Issue

The urgent need to scale up social and clinical support for adults and children with pre-existing palliative care needs during the COVID19 pandemic.

Background

Palliative care (PC) is a holistic approach to care that encompasses the medical, physical, emotional, psychological, spiritual, social and practical needs of patients and their caregivers. Adults and children needing PC, especially in lower- and middle-income countries, often face difficulties in accessing the required services. Their particular vulnerability during the COVID19 pandemic is exacerbated by their inability to access all needed services, treatments, medications, and support for managing life-threatening illness and serious health-related suffering (SHRS).

Key Facts

- Patients with PC needs include those with life-threatening, life-limiting, chronic or acute infectious disease illnesses, which may include cancer, HIV/AIDS, neurodegenerative disorders (including forms of dementia); progressive neuromuscular diseases, metabolic disorders, terminal organ failures, cardiac or respiratory conditions, liver conditions, COVID19 and others. Approximately 21 million children globally have palliative care needs.¹
- Patients with PC needs are often invisible to mainstream society and are 'left behind' by healthcare advocates and policymakers. Many patients fear that mainstream society sees their lives as not 'worth saving'.
- Understanding of the value of palliative care remains limited and patients often access services extremely late in the disease course.
- People with PC needs fear being left alone, isolated from family members and carers, including at the end of life. parents are worried that they will be prevented from accompanying children who may have to be hospitalized and isolated.
- Access to communications technologies and devices is not universal, and patients with PC needs often have limited inability to use devices to stay in touch with loved ones and the outside world.
- Shortages of personal protective equipment (PPE) limit patients' ability to protect themselves, their families and external care professionals (who may be employed directly by the patient). This may force the removal or reduction of outside support, putting pressure on family members or friends to provide care to their loved one and isolate with them.

Current Situation

- Patients are having trouble accessing and paying for medications and supplies. non-oral or highly specialist medicines are increasingly scarce. quarantines are preventing patients from collecting medications and related supplies from hospitals, pharmacies, or providers.
- COVID19 is exacerbating long-standing issues relating to availability of opioid medications in many health systems. including as-needed, hospital-based, or home-care interventions such as palliative radiation, ascites tap, intravenous or subcutaneous infusions, wound care, or specialist palliative procedures.
- Patients and families are facing challenges with practical issues such as suitable housing or accommodation, access to affordable food and other products including basic hygiene items, travel for medically necessary outings, and household income whilst family members (including parents of children with PC needs) unable to work as a result of lockdowns.
- Isolation, including lack of human or familial contact is aggravating social, emotional, and psychological needs due to anxiety and distress related to fear of contracting COVID19 in their already-frail state. individuals with a learning disability or autism on top of PC needs, have additional difficulties understanding and coping with the situation. • Confusion and fear around what treatments hospitals will provide people with pre-existing PC needs if they are infected with COVID19, prevails.
- There is a vacuum of reliable information: guidance have been provided, withdrawn, and changed in some contexts and not provided in others.
- Limited resources are forcing difficult frontline clinical decisions that may mean many with pre-existing PC needs are denied intensive or life-prolonging interventions if they were to become infected with COVID19 or suffer another life-threatening illness during the pandemic. Some health systems are enforcing DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders as a standard protocol without considering individual cases.

Recommendations

- Provide patients with the information necessary to keep themselves safe and to continue to maintain optimal management of their symptoms and conditions, as self-care is vital at this time.
- Continue to support patients even when physical presence is not possible, by telephone or video consultations and check-ins, and to ensure visits are available when medically necessary (with appropriate PPE).
- Ensure access to medications and support patients to access them, including by providing financial assistance and subsidies. • Ensure patients receive alternative interventions or medicines to alleviate symptoms and to manage or control their condition as necessary when standard interventions are unavailable.
- Only raise DNACPR with patients in situations where it is clinically beneficial. ensure conversations involve an open discussion and shared decision making. Decisions cannot be imposed.
- Keep this patient group at the forefront of our minds, as they are the hidden victims of this pandemic. Their health needs and symptoms remain throughout the pandemic as they existed before it, and indeed may well be exacerbated by it.

- Ensure people with existing palliative care needs, and in particular children, are accompanied according to their wishes, including during necessary hospital visits and at the end of life.

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12. Caring for Children with Underlying Serious Health Conditions During COVID19 Pandemic

Authors

Downing J (International Childrens' Palliative Care Network, UK); Chambers L (Together for Short Lives, UK); Daniels A (International Childrens' Palliative Care Network, UK); Doherty M (University of Ottawa, Canada); Drake R (Starship Children's Health, New Zealand); Ferguson J (Together for Short Lives, UK); Kiman R (University of Buenos Aires, Argentina); Lacerda A (Portuguese Institute of Oncology, Lisbon Centre Portugal); Muckaden MA (Tata Memorial Centre, India); Nakawesi J (Mildmay Uganda); Okhuysen-Cawley R (Texas Children's Hospital); Palat G (MJN Institute of Oncology Hyderabad, India); Phillips M (Perth Children's Hospital, Australia); Thompson S (Parent, UK); Vadeboncoeur C (Children's Hospital of Eastern Ontario, Canada).

Issue

There is little clinical data regarding the effect of COVID19 on children with underlying serious health conditions.

Background

Initial data from several countries suggests that children are significantly less affected by COVID19 infection than adults, with the majority of infected children reported to be asymptomatic or experiencing only mild illness. Although critical illness has been relatively rare in children, it is known that adults with underlying serious health conditions are more susceptible to more severe complications, including death, and children with underlying serious health conditions may be similarly at risk. This Briefing Note sets out the recommendations for caring for children with underlying serious health conditions during the COVID19 pandemic

Key Facts

- COVID19 is highly infectious and appropriate infection control practices (including the use of Personal Protective Equipment (PPE) when indicated) is particularly important when interacting with children with underlying serious health conditions, to protect them from contracting COVID19. This may be difficult in resource-poor settings where access to basic necessities such as running water may be limited.
- Families of children with underlying serious health conditions often rely on support from home care, health and social services, special schools, friends, and family, to provide care. The need for physical distancing and changes to care arrangements may disrupt usual support systems which could result in families struggling to care for their child.
- Families may also experience heightened fear and anxiety related to COVID19, including the possibility of transmission to the child or other family members by carers coming into the home. Some families may elect to suspend in-home support to avoid infection.

- Decision-making on the appropriate intensity of care a child with serious underlying health conditions receives should, ideally, be made in advance.

Recommendations

- Ensure the continuation of holistic child and family centered care, albeit, in potentially new, unique, and innovative ways, despite the challenging circumstances of the COVID19 pandemic. Avoid separating children from their carers as much as possible.
- Hope for the best, but plan for the worst. Plan for the possibility that a child with an underlying serious health condition becomes unwell, or his/her main carers become too sick to ensure ongoing care and support for the child.
- Plan for a key family member or trusted contact to assume responsibility in the event that either the child or carer becomes unwell with suspected COVID19 to ensure appropriate access to testing, if available, and continuity of care. Plans should ensure access to essential medicines and supplies for the child's underlying serious health conditions (i.e., opioids, seizure medicines, nutritional feeds etc.).
- Maintain ongoing contact with the primary care clinician that oversees the child's care, in order to optimize continuity of care in the case of COVID19 infection. Virtual care (i.e., telephone, WhatsApp, and other video technologies) can be used whenever possible and can facilitate individual and family support while physical distancing is required.
- Promote timely, life-affirming advance care planning that takes account of the impact of COVID19 infection on the child or their carers. Develop advance care plans (ACPs); particularly those with "Do Not Attempt Resuscitation" orders (DNAR) using individualized, transparent, and compassionate communication. Review existing ACPs already in place in the context of possible COVID19 infection.
- Ensure ACPs are developed using open communication in a life-affirming manner which incorporates and acknowledges the views of the child (if she or he is able and desires to participate) and caregivers.
 - Keep health professionals up to date with available evidence and experiences of others in caring for children with serious underlying health conditions who have contracted COVID19.
- Provide ongoing emotional, social, and spiritual support to children with underlying serious health conditions and their families and recognize the additional stress they may be facing as a group who may be at higher risk of serious complications or death from COVID19.

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13. Symptom Control at the End of Life in Children with COVID19 Infection

Authors

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Issue

Serious COVID19 infection may be rare in children, and clinical data to inform care is limited. All children who become infected with COVID19 should receive appropriate care, symptom management and, when needed, end-of-life care. Children's palliative care (CPC) providers may not be available and alternative care solutions may be required.

Background

Children appear to be significantly less affected by COVID19 infection than adults, with many children asymptomatic or having mild upper respiratory tract symptoms (1). Despite this, health professionals caring for children should be equipped to provide effective symptom management and end-of-life care for all children, including those with underlying serious health conditions. This Briefing Note offers recommendations for managing symptoms at the end-of-life in all children with COVID19 infection.

Key Facts

- Few children with COVID19 infection have required hospitalization, pediatric intensive care unit (PICU) admission or have died, although infants less than 1 year of age and children with underlying serious medical conditions may be at higher risk of developing severe illness (2).
- Symptom management may need to be provided in unique and innovative ways with considerable barriers in having families present when a child with COVID19 is dying.(3)
- Using innovative technology solutions is one option to enable the presence of family members at this time.
- Escalation to intensive care intervention may be undesirable or unavailable for these children but high-quality care focused on impeccable symptom management and comfort remains readily accessible no matter the resource setting.

Recommendations

- The impact of the COVID19 pandemic on end-of-life care must be addressed. Considerations include: (a) advance care planning. (b) end-of-life care may not be possible in the child's/family's preferred place. (c) recognition that limitations on the presence of family members are likely during the child's death and funeral process due to personal, institutional, or governmental mandates.
- Specialized CPC teams must be readily accessible but if not, the child's primary pediatric team or adult palliative care team should offer support and advice.
- Principles for clinical care are: (a) treat reversible causes. (b) manage symptoms. (c) use pharmacological and non-pharmacological strategies.
- Train front-line workers in managing distressing symptoms – remembering that symptoms can be related to COVID19 infection or the underlying serious health condition.

Symptom Management at the end of life for children with COVID19 infection

For managing pain at the end of life in children with COVID19 infection:

Reversible causes	<ul style="list-style-type: none"> • Consider reversible causes • Observe for signs / symptoms of pain
Non-pharmacological measures	<ul style="list-style-type: none"> • Cognitive, behavioral, and physical interventions for pain management results in better pain control • Use nonpharmacological techniques alongside analgesic therapy • A trusting relationship with effective communications between child, family and health professionals is vital to good pain management
Pharmacological measures	<p><u>Mild Pain</u> Use oral paracetamol for children For neonates, paracetamol and sucrose can be used for mild pain Paracetamol - Oral</p> <ul style="list-style-type: none"> • Neonate -10-15mg/kg every 6-8 hours, maximum 60mg/kg/day • Infant or child - 20mg/kg every 4-6 hours, maximum 75mg/kg/day (4g/day) <p>Paracetamol - Rectal</p> <ul style="list-style-type: none"> • Child - 30mg/kg then 20mg/kg every 6 hours <p><u>Moderate to Severe Pain</u> Morphine sulphate - Oral</p> <ul style="list-style-type: none"> • Neonate: Initially 25-50micrograms/kg every 6-8 hours adjusted to response • Child 1–2 months: Initially 50micrograms/kg every 4 hours, adjusted according to response • Child 3–5 months: Initially 50– 100 micrograms/kg every 4 hours, adjusted according to response • Child 6–11 months: Initially 100-200micrograms/kg every 4 hours, adjusted according to response

¹ There is some discussion re the use of NSAIDS in individuals with COVID19. If caring for a child at the end of life, and there is no paracetamol available then NSAIDS can be used alongside other medications as appropriate.

	<ul style="list-style-type: none"> • Child 1–11 years: Initially 200-300 micrograms/kg (initial maximum 5-10 mg) every 4 hours, adjusted according to response • Child 12–17 years: Initially 5–10 mg every 4 hours, adjusted according to response <p>Morphine sulphate – IV/SC</p> <ul style="list-style-type: none"> • Neonate: Initially 25 micrograms/kg every 6-8 hours • Child 1-5 months: Initially 50-100 micrograms/kg every 6 hours • Child 6 months-1 years: Initially 50-100 micrograms/kg every 4 hours • Child 2-11 years: Initially 100 micrograms/kg every 4 hours adjusted according to response, maximum initial dose of 2.5 mg. • Child 12-17 years: Initially 2.5-5 mg every 4 hours (maximum initial dose of 20 mg/24 hours). <p>If morphine or other strong opioids not available, consider tramadol, oxycodone, or other medications for moderate pain</p>
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For managing **breathlessness** at the end of life for children with COVID19:

Reversible causes	<ul style="list-style-type: none"> • Consider reversible causes • Observe for signs/ symptoms of breathlessness or dyspnoea • Consider checking oxygen saturation
Non-pharmacological measures	<ul style="list-style-type: none"> • Manage in a calm reassuring manner to reduce anxiety in child and family • Position child in upright position, as able • Address anxiety by exploration of fears and where appropriate, reassure child and family • Consider using breathing/relaxation techniques and cognitive behavioral strategies • Reduce room temperature • Wear loose clothing • Cool face with a cool flannel or cloth • NB Portable fans are not recommended for use during outbreaks of infection
Pharmacological measures	<ul style="list-style-type: none"> • Humidified oxygen if hypoxemia and available • Opioids to reduce perception of breathlessness: • <u>Use 30-50% of the Morphine dose used for pain</u> (see above) • For anxiety associated with dyspnoea <p>Child 1-9 years:</p> <ul style="list-style-type: none"> • Midazolam buccal 50-100 micrograms/kg PRN (max 2.5mg) single dose (maximum 4 doses/day) <p>Child 10-17 years:</p> <ul style="list-style-type: none"> • Midazolam buccal 1.5-3 mg single dose (maximum 4 doses/day) • Levomepromazine for breathlessness due to agitation/distress: See delirium dosage • Consider lorazepam or clonazepam if other medications are not available

For managing **cough** at the end of life for children with COVID19:

Cough hygiene to minimize risk of transmission	<ul style="list-style-type: none"> • Health professionals to use PPE at all times • Cover nose and mouth with a disposable tissue when coughing, sneezing, wiping, and blowing nose, or cough into your elbow if no tissue available • Dispose of used tissues promptly into clinical waste bin • Clean hands with soap and water after contact with any respiratory secretions
Non-pharmacological measures	<ul style="list-style-type: none"> • Oral fluids • Honey and lemon in warm water • Elevate head whilst sleeping
Pharmacological measures	<ul style="list-style-type: none"> • If history of reactive airways consider salbutamol or ipratropium inhaler/nebulizer. Metered-dose inhalers are preferred • Suppress cough i.e., with Simple Linctus 5-10mls three to four times a day • For persistent irritable cough – morphine sulphate immediate release solution 30-50% of pain dose. If no cough, reduce and stop after 72 hrs.

For managing **fever** at the end of life for children with COVID19:

Non-pharmacological measures	<ul style="list-style-type: none"> • Reduce room temperature • Wear loose clothing • Cool face with a cool flannel or cloth • Keep well hydrated • NB Portable fans are not recommended for use during outbreaks of infection
Pharmacological measures	<ul style="list-style-type: none"> • Paracetamol PO/IV/PR – dose is dependent on age and route

For managing **delirium** at the end of life for children with COVID19:

Reversible causes	<ul style="list-style-type: none"> • Consider reversible causes • Consider increasing pain or hypoxia relief, this may be all that is required to settle the child • Assess and manage a full bladder • Nurse in a calm, peaceful environment with a parent or trusted adult present, ideally in familiar surroundings, but this may not be possible due to nursing restrictions • Use senses that are still intact such as hearing (play favorite music, reading stories) and familiar smells (child's own blanket or soft toy) • Ensure effective communication and reorientation and provide reassurance i.e. ask the family to use touch etc.
Pharmacological measures	<p>First line: Haloperidol</p> <p>By mouth</p> <ul style="list-style-type: none"> • Child 1 month–17 years: 10–20 micrograms/kg every 8–12 hours. maximum 5 mg twice a day. <p>By continuous IV or SC infusion</p> <ul style="list-style-type: none"> • Child 1 month–11 years: Initial dose of 25 micrograms/kg/24 hours (initial maximum 1.5 mg/24hrs). • Child 12–17 years: Initial dose of 1.5 mg/24 hours.

	<p><u>Second line: Levomepromazine</u></p> <p>By Mouth</p> <ul style="list-style-type: none"> • Child 2-11 years: Levomepromazine 50-100 micrograms/kg twice a day PRN • Child 12-17 years: Levomepromazine 3mg twice a day PRN (max dose 25mg/dose) <p>By continuous subcutaneous or intravenous infusion over 24hours:</p> <ul style="list-style-type: none"> • Child 1 year–11 years: Initial dose of 350 micrograms/kg/24 hours (maximum initial dose 12.5 mg); increasing as necessary up to 3 mg/kg/24 hours • Child 12–17 years: Initial dose of 12.5mg/24 hours increasing as necessary up to 200 mg/24 hours. <p>By SC or IV injection:</p> <ul style="list-style-type: none"> • Child 12–17 years: Initial dose of: • Child <35 kg as required dose 2.5 mg given once or twice daily. • Child >35 kg as required dose 5 mg given once or twice daily. • Chlorpromazine is an option in countries where haloperidol and levomepromazine are not available.
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The Association of Pediatric Palliative Medicine Master Formulary is available as a free download, for drug doses and use of medications in children’s palliative care. It is based on evidence and checked by palliative care specialists and pharmacists up to September 2019 (available in English, Ukrainian and Russian). (4)

Engage with your team to ensure comfort is the priority as children approach the end of life. Please ensure written orders reflect this. Unmanaged symptoms at the time of death will add to the distress of the child, family members and clinical staff.

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Disclaimer by authors: These recommendations are for reference and do not supersede clinical judgement. We have attempted to decrease complexity to allow barrier-free use in multiple settings. Evidence supports that appropriate opioid doses do not hasten death when used appropriately. Reassess dosing as child’s condition or level of intervention changes.

Disclaimer by IAHP Press: The information contained in the Briefing Notes on clinical and therapeutic approaches and recommendations should not be relied upon as complete or accurate, nor should it be relied on to suggest a course of treatment for a particular individual. Patients and professionals with health care related questions or concerns are advised to contact experts in the field for clinical guidance.

14. Social Impact of COVID19 on Children with Palliative Care Needs and their Families

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Issue: The urgent need to understand the social impact of COVID19 on children with palliative care needs and their families, in order to mitigate the impact and make provisions for ongoing support.

Background

Due to the nature of COVID19 transmission, most countries have enacted measures to reduce transmission, affecting everyone's lives. Isolation measures most severely impact the most vulnerable members of society, including children with palliative care needs, complex medical conditions, or mental illness. Whilst in some parts of the world, children and their families have access to robust telephone and internet networks, along with technologies such as smartphones, tablets, and computers, in other regions this is not the case, leaving children even more socially isolated from their friends and family. This Briefing Note offers recommendations regarding the mitigation and management of the social impact of COVID19 on children with palliative care needs and their families.

Key Facts

- Physical distancing, shielding, isolation and quarantine are in place in many countries around the world. There are reports from quarantine of negative psychological effects, many of which may be long-lasting.
- Children with palliative care needs and their caregivers are often isolated from family members, friends, carers, schools and social support networks, and this isolation is only compounded by the threat of COVID19 infection and the associated fear and anxiety.
- Families often rely on support from friends, family, schools and health and social care providers to care for their children. Due to the need for shielding and self-isolation, normal support systems are less available, and families can be left struggling at home to care for their children.
- Many parents looking after children with underlying serious health conditions are unable to work, creating serious financial difficulties for families. Arrangements for deliveries of medicines and food must be arranged, potentially for the long term. This is further compounded by difficulties in being

able to reach other family members. Social workers need to be innovative in finding potential solutions.

- It is unknown when social restrictions will be lifted, with some anticipating physical distancing to be in place for 6-9 months or longer, potentially resulting in children and their families living with fear and anxiety for an indefinite period.
- Children and young people with palliative care needs, and their families, may not be able to have the end-of-life care previously planned i.e., the opportunity to make memories or have the funeral and send off, due to the COVID19 pandemic. Families who have been caring for children and young people with serious underlying health conditions for many years have often had 'near misses' leaving them in fear of their child dying from COVID19, potentially alone and in isolation.
- The sudden and constant stream of news reports about the pandemic can cause children to feel worried with this amplified through lack of social interactions with friends and family.
- Movement restriction increases the risk of violence in homes. Home isolation provides power to the abuser with those being abused feeling more trapped and unable to escape. An increased demand for domestic violence services has been prompted by vulnerable families being together 24 hours a day within the home.

Recommendations

- Avoid separating children from their carers whenever possible.
- Ensure that the child continues to receive care from other trusted individuals throughout the pandemic.
- Provide regular contact with parents and carers, through scheduled telephone, video calls or social media, where available. Identify innovative ideas for encouraging ongoing communication with family, friends, and peers.
- Address concerns in an honest, age-appropriate way. Self-regulation and emotion management strategies modelled by adults to children will help to mitigate risks.
- Encourage parents to find ways to discuss the pandemic with their child and explore their concerns using resources from reputable sources such as the Harvard Health Literacy project, which are available in different languages.
- Limit the amount of time children are exposed to the news to help reduce stress.
- Share the following key messages with children: a) the adults in their lives are doing their best to keep them safe. b) there are things that children can do to feel in control and safe, like asking questions, washing their hands, and staying home with their family. and c) emphasize and share that there are positive stories about COVID19, i.e., people have recovered from the virus or are helping others during this difficult time, spreading kindness.
- Establish new routines as appropriate, to help children feel secure, providing time for them to express themselves through play.
- Ensure that all abuse helplines, for both children and adults, remain in service, and are accessible to those in need, along with shelters and other refuges.

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15. Psychological and Spiritual Impact of COVID19 on Children with Palliative Care Needs

Authors

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Issue

The psychological and spiritual impacts of COVID19 on children with palliative care needs are significant, with children being isolated, fearful, anxious, and unclear and uncertain about what is happening at home, in their community and around the world. (1,2)

Background

The high transmissibility of COVID19 has prompted a global response. Isolation measures will most severely impact the most vulnerable members of society, including children with palliative care needs, complex medical conditions, or mental illness. (3,4) Children and families lacking access to electronic media will suffer isolation more profoundly. This Briefing Note offers recommendations regarding the mitigation of the psychological and spiritual impact of COVID19 on children.

Key Facts

- Physical distancing and other protective procedures are in place around the world. Extended quarantine has negative psychological effects, many of which may be long-lasting. Associated rules and precautions, including wearing protective uniforms and performing procedures, create undue stress that can be mitigated by compassionate communication.
- The global COVID19 pandemic is causing widespread fear and stress in adults. Children also have fears of dying, their relatives dying, of the actual infection and access to medical care. School closures disrupt routines, a sense of structure, and peer support, all of which impact on well-being in a significant way. (5)
- Some children live in poor, high-density or remote areas, with little access to water or sanitation and may not have a family or a safe place to live. Children with parents may seek more attachment, placing demands on parents stressed by the pandemic. Knowledge gaps in children and families may promote irritability and anger, increasing the risk of verbal and physical abuse within the home. This time of uncertainty and elevated risk may go on for an indeterminate period. (6)

Recommendations

- Consider the age of children, young people, and those with profound and multiple learning difficulties (PMLD); acknowledge and normalize their anxiety and fears, empower them with age-appropriate information and offer a supportive presence through telephone, WhatsApp, social media etc. Resources such as “My Hero is You: How kids can fight COVID19’ (7), (available in >30 languages) “The Story of the Oyster and the Butterfly: The Corona Virus and Me” (8), “Q is for Quarantine: The ABCs of Coronavirus” (9), “Los Días en que todo se detuvo” (10) and “Hablando con los niños cuando un familiar esta enfermo” or others in your national language may be helpful. A calm parental demeanor is powerful.
- Encourage use of materials such as the “My 2020 COVID19 Time Capsule” to help children document their experience to share with friends and families once social restrictions are lifted.
- Encourage children to find positive ways to express feelings such as fear and sadness. Engaging in a creative activity, such as playing or drawing can introduce a sense of inclusion, safety, structure, and mastery, all of which are beneficial. Honesty and trust, humility, self-compassion, safety, sensitivity, connection, preparedness, community-building, recognition of death as a part of the lifecycle and legacy are vital at this time. Creative approaches to protective gear may make it more child friendly. Provision of mental health services should continue throughout this pandemic, using social media and other technology such as tele counselling and group discussions.
- Seek information from trusted sources so that practical steps can be taken. Balance is especially important. positive and hopeful stories may create a positive environment. Maintain familiar routines in daily life as much as possible, or create new routines, especially if children must stay at home. Activities that promote learning and a sense of belonging are beneficial.
- Encourage a child’s expression of spirituality through a search for meaning and purpose, and through connectedness to themselves, to others, to nature and to a Higher Being. Older children and adolescents may look for the meaning and purpose behind all that is happening. Allow spiritual expression through words, poetry, storytelling, art, dance, play and music. promote communication and interaction with others. build the child’s self-confidence. spend time enjoying nature or bringing plants and animal into the home. assist them to participate in meaningful religious rituals and prayers. and ensure they feel safe, valued, and loved.
- Manage searching questions when a child is dying, either with COVID19 or from their pre-existing life-limiting condition, with truthfulness and compassion.
- Support the family throughout the illness and bereavement through compassionate use of technology. Leverage technology for pastoral care, grief, and bereavement support.
- Train health workers in communication skills commonly used in palliative care and support.

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16. Palliative Care for Older Persons infected with COVID19

Authors

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Issue

Older persons with COVID19 are bearing the brunt of the global pandemic. An overall 20% of all cases are severe or critical, with a crude clinical case fatality rate currently of over 3%, increasing in older age groups and in those with certain underlying conditions. (1) Although many older persons have considerable physical and psychosocial needs, and palliative care is recognized as a component of the right to health, older persons, especially those with non-malignant conditions and living in resource poor areas, have less access to palliative care than the general population.

Background

Older age is often defined as being 60 years and older, but arbitrary chronological age cannot account for the variability in how older persons function and perceive themselves across countries and socio-economic circumstances. However, as people age, they tend to have an increasing number of health conditions. Many of these are non-communicable diseases (NCDs) and degenerative conditions. Many older people also live with a disability. In low- and middle-income countries (LMICs); combinations of communicable and NCDs, are also common in older age. These factors increase the risk of developing more serious illness with COVID19 and of dying from the virus.

Key Facts

- Palliative care is an essential clinical component of COVID19 care (2).
- Older persons with COVID19 symptoms, typically severe breathlessness, agitation, and fever, require either hospital admission for critical care, or referral to palliative care (3).
- Older persons tend to present atypical manifestations of diseases. COVID19 should be suspected where there is sudden change in normal behaviors.
- Men and those with underlying health conditions that affect the cardiovascular, respiratory, and immune systems are at highest risk of becoming seriously ill, with 15% mortality for those over 80 years.¹
- Older persons affected by humanitarian emergencies and living in refugee camps or informal settlements are particularly susceptible to severe symptoms. Living conditions make protective measures like distancing, isolation, and regular handwashing impossible. Lack of health services makes access to care, including palliative care, challenging.

- International law and *opinio juris* (expert legal opinion) recognize that older persons in all settings (home, nursing homes, prison, refugee camps, shelters) have a right to access palliative care services and essential palliative care medicines as a component of the right to the highest attainable standard of health. Given the heightened risk older persons face and scarce health resources, attention needs to be paid to the provision of palliative care services. Older persons have the right to die with dignity and without pain (4).
- Older persons in most countries, especially older women, are disproportionately likely to experience poverty, limiting their access to affordable healthcare, including palliative care, medicines, and essential equipment to support patients with COVID19. Older women are often informal caregivers. Older men and women caregivers may be exposed to the virus if caring for an infected family member without adequate Personal Protective Equipment (PPE).
- Persons with dementia with palliative care needs have insufficient access to optimal palliative care (5). They may find it difficult to understand and comply with COVID19 quarantine and public health messages, and some will require extra assistance with personal care at home or in nursing homes.
- Palliative care services (at home, in hospitals or in hospices) can be adapted to respond rapidly and flexibly in the COVID19 context (6).
- Older people, particularly in LMICs, have practical concerns such as ability to pay for funerals, who will look after children and how to access food.
- Telecommunications platforms and hand-held devices can help older persons and loved ones maintain contact especially during the dying process (6).

Current Status

- Most older persons infected with COVID19 remain at home in quarantine. Their care is managed by family members, such as a spouse, who may also be an older person.
- Large numbers of older persons, predominantly women, are living alone. They face COVID19 with insufficient family or neighborhood support.
- COVID19 restrictions are reducing care available from families, neighbors, social and personal care services that allow older persons, including those living with disabilities, to manage at home.
- Official restrictions, including physical distancing, are adversely impacting the well-being and mental health of older people, especially those living alone or in nursing homes.
- Evidence from a number of countries shows that residents of nursing homes infected with COVID19 have high mortality.
- Ageist assumptions and practices reflected in triage decisions are influencing older persons' access to palliative care and other healthcare services in the context of COVID19.

Recommendations

- Explicitly address palliative care needs of older persons including those with dementia, and their families, in all COVID19 policies and settings.
- Provide older persons in LMICs who are looking after families with sufficient financial resources.

- Provide nursing home staff with sufficient knowledge and resources to integrate basic palliative and end-of-life care.
- Ensure that nursing home policies balance the need to protect older and at-risk residents with their needs for family connection as well as the important oversight that visitors provide.
- Invite older persons to discuss advance care plans to determine care preferences and goals, such as do not attempt cardiopulmonary resuscitation orders.
- Use telemedicine and videoconferencing to facilitate communications with older persons in home settings and institutions as appropriate and evaluate their efficacy.
- Use palliative care techniques to communicate with families and support older patients dying in critical and palliative care settings.
- Provide WHO recommended infection control procedures and other guidance on PPE, as well as psycho-social and spiritual support to staff in hospitals, nursing homes, hospices, and community settings to ensure well-being and resilience <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance>

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17. Palliative Care in Refugee Camps and Humanitarian Crises

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Issue

Palliative care services in refugee camps and sites of humanitarian crises have not been made essential components of pandemic response planning, including for COVID19.

Background

Palliative care aims to prevent and relieve serious health-related pain and suffering - physical, emotional, social, spiritual, practical - associated with chronic or life-threatening illnesses and to promote dignity in suffering, death and dying. In the COVID19 pandemic, communities worldwide are facing care needs, pain, suffering and death that exceed the capacities of most health systems. Basic palliative care can alleviate that suffering, even in humanitarian circumstances where treatment options are limited, or difficult resource allocation decisions have to be made. Humanitarian crises reduce palliative care to its core, yet suffering can still be relieved in small but powerful ways, such as the offering of kind words, attentive listening, or simply sitting with a dying patient. Even when it appears that “nothing more can be done”, palliative care providers can work with patients and their families to document individuals’ experiences witness, and remember, to serve as resources for future advocacy.

Key Facts

- Access to infection control and isolation measures are exceptionally hard to achieve in overcrowded refugee camps or dense urban settings. Intensive care and ventilator support are rarely available in these contexts.
- Access to food, shelter, water, and sanitation are often prioritized alongside, and sometimes before, health care interventions. Palliative care - which for patients with severe health-related suffering or who are dying may be the only realistic support option - can adapt naturally to such circumstances.
- Patients with pre-existing palliative care needs, those whose pre-crisis care has been interrupted, and those with a deteriorating COVID19 infection for whom critical care interventions are ineffective, inappropriate, unavailable, or discontinued due to resource limitations, need palliative care.
- Multidisciplinary teams that may include lay health workers or volunteers from local communities can be trained to provide palliative care. Humanitarian health workers are skilled at providing treatment and care during crises, including in disease epidemics such as Ebola.
- Palliative care practitioners can offer crucial support to colleagues in ethical decision making, setting care goals, and managing emotional, moral, and spiritual distress.

- Essential medicines (i.e., morphine); as listed in the WHO Essential package of palliative care for humanitarian emergencies and crises, are needed to relieve pain, breathlessness, and other symptoms.
- New palliative care challenges arise from the sudden onset of many COVID19 infections, and the physical distancing restrictions and protective equipment that limit opportunities to accompany the dying and attend funerals.
- Holistic compassionate care can be provided even under these challenging circumstances, by increased use of nonverbal communication (through eyes, voice, and body language) and technology (i.e., mobile phones and tablets). The latter can also enable connection and mutual support between patients and families.

Current Status

Palliative care is not an integral part of humanitarian and emergency responses, including in the COVID19 pandemic, as humanitarian health workers and planners are still unfamiliar with its essential role. This is especially the case in low- and middle-income countries where most humanitarian crises, now exacerbated, are experienced. Unfamiliar clinical situations and challenging ethical dilemmas arising in palliative care during the COVID19 pandemic are, however, a common global experience. The COVID19 pandemic is presenting health and social care workers with new stressful, or even traumatic, situations, including resource allocation decisions, dealing with multiple deaths, and fear of dying or endangering their own families.

Recommendations

- Integrate adequately resourced palliative care strategies into all pandemic responses.
- Integrate palliative care provision into existing health and social care systems and the broader humanitarian health response.
- Develop guidelines on palliative care provision in humanitarian crises, specifically for vulnerable groups (i.e., children, older persons, ethnic minorities, and persons with mental health conditions, disabilities, and pre-existing comorbidities).
- Ensure availability of palliative care medications listed in the Essential package of palliative care for humanitarian emergencies and crises, including opioids.
- Enable rapid response palliative care teams, supported by prior planning, guidelines, resources, and medications, to mitigate the negative impact of a pandemic.
- Expedite training for all clinicians and humanitarian health workers in the prescription and administration of essential palliative care medicines, definition of care goals, compassionate communication, and culturally sensitive grief and bereavement support, including through online courses.
- Train community members to provide psychosocial support.
- Conduct research on palliative care in humanitarian contexts under international ethical guidance, prioritizing the best interests of patients who should not be overburdened but supported if they are willing and express a wish to help others through research. Their contributions should be gratefully acknowledged.

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18. Meeting the Palliative Care needs of People with Physical and Intellectual Disabilities

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Issue

The COVID19 pandemic is intensifying existing health system inequities associated with disabilities (1). Persons with physical and intellectual disabilities, both children and adults, are likely to become more vulnerable due to COVID19.

Background

One billion people worldwide are living with a disability: 46% are older than 60, and 80% live in a developing country. Palliative care supports the dignity of persons with disabilities, who are often subjected to discrimination, abuse (physical, emotional, and sexual) and social exclusion (2). Disability is strongly associated with increased rates of multidimensional poverty, decreased rates of education and employment, and higher medical expenses (3). The pre-pandemic world was already one of isolation for many people with disabilities. (4) In many countries persons with disabilities (PWD) do not receive palliative care and health care staff do not understand the need for palliative care for persons with disabilities. Communication difficulties result in undetected pain and failure to report symptoms, leading to deterioration of physical and/or mental health. Spiritual support in palliative care is often neglected in the care of PWD especially those with intellectual or communication disabilities.

Key Facts

- Palliative care is a component of the human right to health, which includes persons with disabilities (5).
- Article 25 of the Convention of the Rights of Persons with Disabilities recognizes that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. (5)
- PWD are three times more likely to have another underlying illness than adults without disabilities, increasing their risk to become severely ill (6).
- Personal Protective Equipment can exacerbate communication difficulties for persons with disabilities as they will be unable to lip-read or interpret body language.
- PWD often depend on family or friends to collect money from accounts, increasing the risk of financial abuse. They could be denied food and basic needs if resources become scarce.
- Individuals living in institutions are more likely to contract COVID19, especially if these facilities are overcrowded and unsanitary. (7).
- Certain disabilities cause an increase in sexual needs, intensified in stressful situations. Lockdown and isolation scenarios may increase sexual needs, leading to frustration and aggression.

Current Status

- Resources for treatment of pre-existing conditions have become unavailable or difficult to obtain, aggravating existing conditions.
- Challenges of implementing basic protective measures such as regular hand washing, physical distancing, and inability to access PPE, are putting PWD with underlying medical conditions and co-morbidities at increased risk of serious illness if infected with COVID19.
- PWD in quarantine are at an increased risk of infection from paid caregivers who use public transport or engage in other social interactions.
- PWD report more physical and emotional stress as a result of difficulties accessing health care and medications.
- PWD in Low-to-Middle-Income Countries (LMICS) or resource limited health systems fear not being able to access intensive care if they become infected with COVID19 or experience any other health crisis.
- PWD are experiencing more isolation than usual as a result of the pandemic.

Recommendations

- Ensure that governments and agencies are held accountable for the provision of palliative care for PWD during COVID19 to improve quality of life.
- Ensure those with pre-existing conditions, including those in need of palliative care, continue to receive treatment and support without disruption.
- Train healthcare workers on the holistic needs of persons (children and adults) with disabilities.
- Establish contact between the person with disabilities and primary carers via electronic media if possible.
- Obtain input from primary carers on communication techniques and typical behavior patterns to enable detection of pain or other health concerns. Use simple and clear language and avoid medical terms as far as possible.
- Ensure adequate communication resources (including braille, sign-language interpreters, communication boards and pictures) where needed.
- Discuss treatment preferences and end of life care – involve primary carers for advance care planning if needed.
- Ensure adequate spiritual and psychosocial support and enable PWD to access mental health services.
- Include PWD in all health care planning, including for COVID19.
- Integrate education on sexuality and PWD in palliative care programs.
- Ensure that PWD can continue to contribute to society.
- Include access for PWD in all health care facilities.

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19. The role of tele-medicine: Remote access to patients, caregivers and health workers

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Issue

Patients with serious illness can experience significant suffering due to pain or other sources of distress, which can be managed effectively by palliative care. The COVID19 pandemic has created challenges to accessing palliative care, leading to increased suffering in this population.

Background

Although palliative care has been shown to improve quality of life, reduce suffering and reduce costs to healthcare systems, it remains poorly developed in most LMICs with limited services accessible to only a small fraction of the people who need it. The risk of infection from COVID19, with associated lock downs, physical distancing requirements and limited availability of PPE have affected access to healthcare in general and further reduced access to palliative care. Telehealth may provide a solution to meeting the growing demands of palliative care services by connecting patients to providers and supporting collaborations between health providers across geographical regions with limited resources.

Key Facts

- Telemedicine is defined as the use of telephone, computer software, and video-based services to facilitate patient-to-provider and provider-to provider communication.
- This approach to the delivery of palliative care services rapidly expanded in recent years prior to the COVID19 pandemic.
- Telemedicine is a feasible, acceptable, and usable approach for patients and healthcare professionals. It has been shown to improve symptom management, reduce hospital admissions and patient mortality, and improve the quality of life of patients and the satisfaction of families with care.
- Telehealth complements direct face-to-face patient care and can be a useful alternative when health care cannot be delivered in person.
- Access to care by telehealth overrides some obstacles facing underprivileged or rural areas as well as the hurdle of transportation to reach a healthcare facility.
- Challenges of telehealth include:
 - limited access to technology and connectivity
 - concerns for maintenance of patient privacy

- lack of training of healthcare workers on digital platforms
- absence of a framework for budgeting and billing for telehealth services
- Lack of access can increase health disparities.
- Telemedicine does not eliminate the need for in-person consultations which can be invaluable in the palliative care population.

Current Status

- The COVID19 pandemic has led to the rapid growth of telemedicine to support the provision of health care services at a distance. Communication technologies have been used to connect providers to patients in virtual visits, patients to family members when they are hospitalized, and providers to each other for expert consultations.
- Telehealth has also been used to deliver essential palliative care components such as existential/spiritual care as well as grief and brief bereavement support at the end of life for patients in isolation.
- There remains a lack of evaluation of telehealth interventions for palliative care

Recommendations

- Facilitate and encourage telehealth programs.
- Integrate existing digital health platforms to facilitate patient-physician interaction and communication among healthcare teams to facilitate comprehensive, timely and high-quality care.
- Engage technology partners to equip community health workers and/or patients with telehealth capabilities to virtually conduct home-based palliative care activities.
- Enable families to virtually visit and partake in health decisions with loved ones, especially at the end of life to address the almost universal fear of dying alone.
- Train and develop existing workforce to provide care using telehealth and develop script to perform virtual conversations.
- Identify mechanism(s) to complete advanced directives virtually with patients in the community and ensure availability of the AD to emergency services and health care workers if necessary.
- Create protocols to ensure patient consent, safety, and privacy.
- Integrate telehealth into existing billing and quality management schemes.
- Continue to use and develop telehealth once the COVID19 pandemic is controlled.

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20. Self-Care for Caregivers during the COVID19 Pandemic

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Issue

Hospice and palliative care providers in the COVID19 pandemic face new and dramatic challenges to self-care, and risk moral distress, burnout, and traumatic stress.

Background

The COVID19 pandemic is creating enormous challenges for health care systems and health care providers worldwide. Providers of care are facing excessive workloads, the threat of being infected or infecting others, a lack of personal protective equipment, diminished support from overworked team members, and the challenges of providing person-centered compassionate care via telemedicine. In addition, there are pressures to return to work after full or partial recovery from COVID19 while dealing with residual symptoms including fatigue, the trauma of having had the disease, possibly having been ventilated and facing personal mortality, and possible neurological changes. At the same time, they have little time for the self-care and stress management practices that can enhance their resilience and coping capacity and prevent burnout and traumatic stress.

Key Facts

- A wide range of self-care practices can significantly reduce the incidence of burnout and traumatic stress in hospice and palliative care providers.
- End-of-life professionals report that work overload and lack of an opportunity to grieve work-related losses are their two greatest stressors.
- Social support within health care teams is essential to the well-being and efficacy of team members.
- Preliminary research indicates that those who care directly for COVID19 patients and families should pay greater attention to self-care to prevent burnout and traumatic stress.

Current Status

- Self-care practices (i.e., seeking social support, music therapy, exercising, proper nutrition, meditation, taking time off, setting limits) are undermined in the COVID19 emergency.
- Work overload, cumulative loss and exposure to repeated trauma are common in care of COVID19 patients.
- Some providers will be more vulnerable to stressors because of previous life experiences or health issues.

- Lockdown/shelter-in-place and quarantine orders to ensure physical distancing interrupt many of the resilience enhancing and self-care practices that reduce stress and prevent provider burnout.
- Relationship disruption, and inability to physically care for patients (i.e., in long-term care facilities); represent significant stressors for palliative care providers.
- Isolation of staff from their own family members prevents provision of critical social support.
- Disruption of team member roles and supportive relationships is presenting challenges.
- Caregivers may feel guilty taking time away from the clinical environment to restore themselves when others are working even longer hours.
- The physical strain of wearing protective equipment (dehydration, heat, exhaustion) is accelerating the need for enhanced stress management and self-care practices.
- Scarce resources are resulting in conflict within organizations, undermining team functioning and support.

Recommendations

- Ensure that demands on the palliative care workforce are carefully monitored and adjusted to permit essential self-care and to maximize care of COVID19 patients and families.
- Ensure workplace hygiene, appropriate personal protective equipment, and communication of safety precautions taken to providers.
- Facilitate improved virtual and direct communication between palliative care team members to increase technical and emotional support among team members.
- Provide support and information to providers and their families to assist them with strategies and practices for safely sheltering and quarantining.
- Enhance direct-to-consumer telemedicine training and practices to reduce clinician burnout.
- Offer extensive supervision to palliative care providers that solicits feedback and input related to care experiences and needs.
- Support meaning making and strengthen the sense of purpose that are key for care providers.
- Set up measures to mitigate stigma at community level for health workers caring for COVID19 patients.
- Provide mental health services to address COVID19 psychological morbidity.
- Recognize that different caregivers have different needs for support and that support will need to be continued for staff after the pandemic resolves in order to prevent PTSD.
- Monitor staff returning from being ill with COVID19 to make sure their needs are being recognized and addressed and that their physical and mental health are not being neglected in the urge to have them back at work.
- Recognize that there may be a need for additional bereavement support for those who experience a death through COVID19.

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21. “Leaving No One Behind”: Valuing & Strengthening Palliative Nursing in the time of COVID19

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Issue

Globally, nurses have been at the forefront of the COVID19 pandemic. Their contribution has highlighted the particular competencies and skills that palliative care nurses (PCN) possess.

Background

The COVID19 pandemic is creating enormous challenges for health care systems (HCS) globally. It also presents opportunities. Throughout the pandemic, nursing has been at the forefront of care provision, giving nurses the opportunity to demonstrate the knowledge, skills, and commitment required to provide high quality evidence-based care. The pandemic has also exposed the challenges nurses face, including excessive workloads, redeployment to areas requiring new or different competencies, the risk of being infected or infecting others, and often working without the recommended Personal Protective Equipment (PPE). It has also shown that nurses are working in HCS where the role and value of nursing is not always appreciated. This Briefing Note sets out the recommendations for recognizing the unique value of PCN.

Key Facts

- Nurses are critical to “leaving no one behind” and the global response to the COVID19 pandemic. During the pandemic PCN’s have:
- The opportunity to showcase their unique and innovative skill set, in particular, the holistic approach to care that is the cornerstone of PC. Often this contribution is not recognized or diminished, limiting opportunities for leadership development.
- Utilized their experience in dealing with complex problems and decisions and are instrumental in balancing the holistic needs of patients, their families, and staff caring for them, including grief and bereavement.
- Demonstrated that PC is not a luxury but a human right and an essential response to COVID19.
- Shown that all nurses caring directly for patients with COVID19 are at increased risk of stress and burnout and need to ensure that they are offered opportunities for self-care.

Current Status

- Nurses are the largest occupational group in the HCS, accounting for approximately 59% of health professionals globally. In 2018, there was a global shortage of 5.9 million nurses, with a shortage of 5.3 million (89%) concentrated in low-and middle-income countries (LMICs).
- Approximately 90% of the global nursing workforce is female. Gender-based issues prevalent in nursing include pay gaps, minimum wage, inequality, discrimination in promotion, leadership and decision-making positions, and lack of social protection. Nurses are experiencing a heavy workload, cumulative loss, and exposure to repeated trauma.
- In many countries, particularly LMICs, nurses fear for their safety and are providing care without adequate PPE thus putting themselves, their patients, and their families at risk. To minimize risks, some nurses are isolated from their own family members in order to continue to provide care.
- Some PCN's have been redeployed from their usual places of work and have had to rapidly learn new skills.
- Retired nurses and nursing academics have returned to clinical practice to support the COVID19 response.
- Coping with restrictions such as 'lockdown', quarantine and a lack of public transport is making it difficult for nurses to get to work, causing increased stress and expense.
- Some nurses caring for COVID19 patients have been stigmatized.
- In many LMICs trained community care/ health workers are performing care traditionally provided by nurses both in the community, in hospitals, etc.

Recommendations

- Recognize the important and unique role of nurses, particularly PCN, as an essential part of the COVID19 pandemic response.
- Ensure PC is seen as an integral component of nursing practice, regardless of specialty or setting.
- Provide nurses with the appropriate resources to carry out their work efficiently, effectively, and safely.
- Provide education and training that enables all nurses to acquire adequate competencies for the management of COVID19, including prevention, assessment, treatment, and PC.
- Support and mentor retired nurses and nursing academics returning to clinical practice to support the COVID19 response to ensure that they are competent in the work being undertaken.
- Provide all nurses with the appropriate PPE required to carry out their work.
- Protect nurses from gender-based issues at the workplace where they should feel safe and secure to carry out their nursing roles.
- Provide transport for nurses to get to, and from their places of work without increased personal financial burden and to reduce the risk of their becoming infected.
- Provide supervision and mentorship of nurses without PC training by PCN.

- Ensure that nurses are paid for all of the hours that they are working, and review nursing salaries in the light of the COVID19 pandemic.
- Ensure nurses have adequate time off work to enable self-care and resilience, and access to counselling.
- Invest in education, training, jobs, and leadership training for PCN.

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22. Advocating for Integration of Palliative Care into National COVID19 Responses: Challenges and Successes

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Issue

Health advocacy includes educating policymakers and the public about evidence-based policy. (1) Palliative care (PC) advocates at the national level need support and guidance to hold their policymakers accountable for commitments made at the international level to integrate PC into their national COVID19 response plans, health policies, and universal health coverage (UHC) strategies.

Background

The pandemic has catapulted serious health related suffering (SHS); end of life care and dying into public consciousness. It has exposed the costs of chronic under-resourcing of PC for management of both COVID19 patients and those with other forms of SHS. Although UN member states have committed – through the recent World Health Assembly (WHA) COVID19 Resolution, (2,3) and others - to provide PC as an essential service along with prevention, treatment, and rehabilitation, few governments have yet to fully implement those commitments. National implementation requires informed and sustained advocacy to persuade and support policymakers that they can deliver on their international commitments and make PC available to all who need it, even during a pandemic. The current crisis may even prove an opportunity to secure additional funds and commitment to PC as leaders respond to growing political pressure to reform health systems and build back better.

Key Facts

- National PC organizations need support and guidance to hold their policymakers accountable for commitments made at the international level, to integrate PC into their national COVID19 response plans, policies, and universal health coverage strategies.
- National PC organizations and/or local leaders are the responsible agents for liaising with their elected national officials and civil servants. They can:
- Hold their governments accountable for commitments to provide essential PC medicines and services -- including for children, persons with disabilities, older persons, refugees, migrants, prisoners, and other vulnerable populations.
- Include key stakeholders: providers, patients, and caregivers in advocacy,
- Provide policymakers and media contacts with information about human rights standards and technical support available through UN Agencies such as the Human Rights Council, the World Health

Organization (WHO); the United Nations Office of Drugs and Crime (UNODC); and the International Narcotics Control Board (INCB). (4)

- International PC organizations can support the advocacy of national associations with resources, technical training, and ethics consultations upon request. They can always advocate, but never lobby.

Current Status

- PC literacy among policymakers, the media, and the public, remains low and in some instances non-existent, despite consistent efforts of global, regional, and national advocates to raise awareness of its benefits as an essential public health service.
- Community PC providers and national professional associations are struggling to survive financially in the face of reduced donor funding for service delivery and advocacy.
- Many government offices are closed or under restriction, and advocates are unable to access policymakers and media contacts in the traditional face to face method, although in some settings governments have approached PC organizations to help with the response.
- PC providers are being redeployed to critical care and other positions, in some instances without adequate orientation or PPE to protect themselves and their patients.
- The pandemic is disrupting maternal and child health, diagnostics, treatment, and PC for persons with, cancer, disabilities, NCDs, HIV/AIDs, TB, and other serious (non-pandemic related) health conditions, causing severe distress to affected patients and families, and escalating rates of SHS.
- The pandemic environment is dominated by discussions on non-pharmaceutical prevention measures such as social/ physical distancing and funding of prevention, vaccines, and treatment, without reference to PC needs of population, further making policy uptake of PC problematic.

Recommendations

- Clarify your advocacy messages: for example:
 - “We have developed an inventory of available services and trained providers so our national membership can help integrate PC into the national COVID19 response from the community to the tertiary level.”
 - “We can deliver basic PC training online and in person to the national health workforce, including to community health volunteers, if you develop a budget line and regulations to support us”.
 - “We can support critical care providers by facilitating difficult conversations with patients and providing bereavement care for families”.
- Become more visible:
 - Join national and regional networks (i.e., for UHC, rights of older persons and persons with disabilities, etc.) and
 - Identify allies among local NGOs, including HIV and NCD patient groups, and faith-based organizations.

- Offer to advocate for patients with PC needs, persons with disabilities, and older persons in clinical situations.
- Designate at least one member as an advocacy point person. this person should:
 - Familiarize themselves with existing PC Recommendations for national and regional PC organizations guidelines and resources⁵ for COVID19 and apply them to the national context in the form of evidence-based recommendations.
 - Refer to the WHO guidelines to demonstrate that PC can alleviate COVID19 related suffering alongside prevention and treatment. (5)
 - Identify key public health decision makers and design advocacy efforts to engage with them.
- Ask contacts you may have in common to introduce you, or write directly, presenting material about the issues and unmet needs in your community.
- Identify and develop relationships with opinion leaders/journalists.
- Invite media contacts and policymakers to accompany teams on home, telemedicine, and clinic visits as appropriate.
- Build a social media presence and collaborate with communications experts (at regional, national, and subnational levels).
- Regularly document and evaluate challenges and accomplishments.
- If one advocacy strategy is not working, try new tactics in consultation with membership and direct stakeholders.
- Learn and practice regular self-care and support your team! Ask for help when you need it.

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23. Palliative Care for LGBT+ Persons in the Time of COVID19

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Issue

The COVID19 pandemic poses new physical, psychological, and social threats, compounding the vulnerability of LGBT+(a) people to access health care. It has complicated their access to palliative care services, which for many were unavailable prior to COVID19.

Background

Key populations, including LGBT+ people, have significantly lower uptake of essential health services due to social marginalization, legal and social conditions, stigma within health systems, and human rights violations. In some countries, LGBT+ people and their relationships are socially accepted, have legal protection, and health care is delivered within an inclusive framework of access and delivery. In other countries' LGBT+ people are not accepted, are socially excluded, may face violence and punishment under the law, and access to health care such as PC is difficult if their sexual identity or gender history is known. Discrimination against sexual and gender minorities is known to disproportionately expose them to some serious illnesses (such as HIV, other sexually transmitted illnesses, and some cancers); often under-diagnosed due to the failure of health workers to explore sexual preferences.¹ Thus LGBT+ people may have greater needs for PC due to health behaviors linked to minority group stress secondary to stigma, and access to, and outcomes of, health and social care is generally poorer.

Key Facts

- There is a high level of stigma, exclusion, and social and culture marginalization around the world for LGBT+ people who are a diverse group of individuals. This needs to be overcome to enable equitable access to PC services. (1,2,3,4)
- Health systems in general do not prioritize the needs of key populations such as LGBT+ people. medical attention may be delayed, dependent on others to seek and pay for care (5). Resources and medicines may be restricted, and they risk discrimination by health workers, all of which may result in delay in seeking treatment for COVID19.
- LGBT+ people have a history of dehumanizing and marginalizing experiences when interacting with health care professionals who lack the training to respond to the communities needs⁶
- Inequities impacting LGBT+ people are particularly detrimental during EOL care, time of death and bereavement thus impacting PC access. (6)

- This, compounded by the additional challenges from COVID19 and restrictions on care, mean that LGBT+ people are particularly at risk of poor access to PC at this time. (4)

Current Status

- Significant health inequities exist for LGBT+ people, and their challenges and needs are not being recognized, which place many individuals at particularly high risk for COVID19 related mortality.
- Due to their vulnerability, the burden of Serious Health related Suffering (SHS) requiring PC may be greater amongst LGBT+ people due to pre-existing higher prevalence of mental health problems (due to stigma) and social exclusion.
- Existing public health crises (i.e., access to medicines, housing) continue as the world contends with COVID19. • LGBT+ people, particularly youths, are experiencing extra stressors due to LGBT+ intrapersonal, interpersonal, and structural challenges due to COVID19, such as being isolated without their partner or with unsupportive or violent families, loss of in-person identity-based socialization and support, (7) raising concerns for mental health issues.

Recommendations

- Train all health and social care professionals in anti-discriminatory practice, and detailed assessment must identify social support systems, sexual preferences, partner information etc. (8)
- Integrate PC into public health systems and ensure public health measures are sensitive to the needs of LGBT+ people and focus on equal rights to health and other needs, including inclusive PC.
- Implement the following evidence-based and simple recommendations to improve care for LGBT+ people requiring PC at the individual and institutional level³
- Individual level: a) avoid using heterosexually framed or assumption-laden language. b) demonstrate sensitivity in exploration of sexual orientation or gender history. c) respect individuals' preferences regarding disclosure of sexual identity or gender history. d) carefully explore intimate relationships and significant others, including biological and chosen family (friends). and e) explicitly include partners and/or significant others in discussions.
- Service/institutional level: a) make clear statement of policies and procedures related to discrimination. b) include content regarding LGBT+ people in training on diversity and discrimination. c) increase LGBT+ visibility in materials (in written content and images). d) provide explicit markers of inclusion (i.e., rainbow lanyards or pin badges). and e) initiate partnerships and/or engagement with LGBT+ community groups.
- Ensure PC professionals approach every encounter with a COVID19-positive patient using LGBT+ inclusive language, regardless of the patient's gender expression/identity or presumed sexual orientation (4,5).
- Assume every LGBT+ patient infected with COVID19 may need a surrogate decision maker to step in at some point in their care and that family dynamics around issues of health care decision making may be complicated (4)
- Ask relevant questions deemed necessary to the care and condition of the patient and listen, acknowledge, and respond empathically and non-judgmentally to the answers. avoid questions aimed to appease personal curiosity about a patient's body, experience, or life (4)

- Engage in self-reflection about individual- and system-level conscious/unconscious LGBT+ biases. The intent of inclusive practice is not to eliminate bias but to acknowledge it and identify how it hinders the provision of ethically based, human-centered PC services across the continuum and lifespan.
- Acknowledge, approach, and report any situation of violence LGBT+ people are exposed to.
- Advocate for policy changes at service, institutional, local, regional, and national levels to eradicate discriminatory policies against LGBT+ people that prevent health equity and delay access to PC.

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24. Vulnerable Populations in COVID19: Palliative Care for Detainees in Custodial Settings

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Issue

The COVID19 pandemic is significantly increasing the demand for palliative care (PC); a service that is still precarious, or non-existent, in custodial settings worldwide. Older detainees with multiple co-morbidities, and those with chronic conditions who lack access to PC are particularly vulnerable to serious health related suffering (SHS). The added pressure of the COVID19 pandemic on health systems in general, and on custodial settings in particular, further reduces detainees' access to basic health services, in violation of existing international human rights standards. (1)

Background

The revised Standard Minimum Rules for the Treatment of Prisoners, adopted unanimously by the UN General Assembly, also known as the 'Nelson Mandela Rules,' stipulate that *“prisoners should enjoy the same standards of health care that are available in the community. and in cases where prisoners are suspected of having contagious diseases [particular attention shall be paid to] providing for the clinical isolation and adequate treatment of those prisoners during the infectious period.”* However, the quality of health care in custodial settings is frequently below the national average in most countries, and access to PC is even more limited. Lack of systematic research and global mapping of services in these settings challenges health care responses to pandemic related needs, including PC needs, of this vulnerable population. Correctional health is public health: staff and contractors, any of whom might carry the virus, are vectors for the spread of infection both within and outside custodial settings, potentially overwhelming community healthcare systems, including the few that deliver PC. (2) Incarceration itself, not loss of basic health care, is the intended punishment for criminal acts.

Key Facts

- Palliative care is the active holistic care of individuals across all ages with serious health related suffering due to severe illness, and especially of those near the end of life. (3)
- On May 19, 2020, the 73rd World Health Assembly adopted Resolution 73/1, directing governments to “provide access to safe testing, treatment, and palliative care for COVID19, paying particular attention to the protection of those with pre-existing health conditions, older people, and other people at risk (...)” (4)
- The proportion of persons requiring PC and EOL care in custodial settings is higher than that found in the general population.

- Legal availability of essential PC medicines containing controlled substances used to manage severe pain and breathlessness is often extremely restricted in prison settings, and is determined by the prison warden, rather than medical professionals. (5)
- Globally, more than 11 million men, women, and children are held in jails, prisons and detention centers, environments unsuited to COVID19 infection prevention and control measures.
- Older persons, many of whom suffer from chronic conditions, are the fastest-growing cohort of detainees in high-income countries.
- Incarceration implies many losses: of freedom, work, family, and often of long-term friends who die behind bars. Few custodial settings offer bereavement services to help detainees cope with these losses.
- The most common facilitators of good PC and EOL care for detainees are the fostering of close relationships, particularly with families and other inmates (including inmate hospice volunteers) and compassionate release for those facing EOL.

Current Status

- In countries that test prisoners, numbers of reported positive COVID19 cases are spiking. many countries without testing programs are not reporting.
- Although authorities in many countries are releasing detainees into the community to slow transmission of the virus behind bars, many medically vulnerable persons still remain in custody.
- Worldwide, the few clinics, hospitals, and hospices that provide PC to persons in both custodial and community settings, have cut services for all patients, either closing down completely, providing only telemedicine visits, or diverting resources to critical care for COVID19 patients.
- Since the majority of PC programs in prisons rely on peer caregivers for service delivery, those with advanced conditions and facing EOL are at high risk of contagion.

Recommendations

For governments

- Embed both prison health and PC in all COVID19 policy responses.
- Ensure adequate availability of PC and PC medicines at community healthcare facilities for all detained persons in need per the 'Nelson Mandela Rules'.
- Reduce jail and prison populations, considering non-custodial sentences and prioritizing for release detainees who test negative for the virus, including minors, older persons, pregnant women, otherwise medically vulnerable persons with life-limiting conditions requiring PC, and their caregivers.
- Operationalize and streamline compassionate release regulations and, where these are unavailable, review and revise existing laws as appropriate.
- Ensure that released detainees with chronic conditions are linked to community services for basic healthcare, and socio-economic support.

For custodial authorities:

- Ensure that seriously ill detainees receive PC by providing health facility staff with basic training in PC and use of essential PC medicines and or providing transport to a community health facility where PC is available.
- Ensure adequate availability of essential PC medicines, particularly oral morphine, in all prison health facilities treating seriously ill detainees.
- Regularly test all detainees and staff for the virus and take appropriate measures to isolate those who are infected to prevent further transmission.
- Distribute and mandate use of adequate Personal Protection Equipment (PPE); soap, and disinfecting agents by detainees and staff.

For civil society organizations and families of incarcerated persons:

- Advocate for increased access to PC in prisons worldwide.
- Petition governments and prison authorities to increase testing, activate broad compassionate release programs, and facilitate communications and telephone calls from detainees to loved ones on the outside.

Further Reading

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25. Palliative Care for those Experiencing Homelessness in the Time of COVID19

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Issue

High rates of chronic disease among people experiencing homelessness (PEH) places them at a higher risk of death from COVID19 infection. The pandemic poses new physical, psychological, and social threats, compounding their vulnerability and complicating their access to palliative care (PC) services, which were already inadequate prior to COVID19.

Background

Groups at high risk of COVID19 are disproportionately represented among PEH (1,2) (i.e., older persons, immunocompromised, those with chronic illness etc.). The homeless population is comprised of individuals who often experience social and health inequities including, but not limited to, sex workers, people living with mental illness, older persons, women, sexual and gender minorities, persons with disabilities, people who use drugs (PWUD); street children, people living in poverty, displaced persons i.e., due to a humanitarian crisis, persons who have been abandoned, and those unable to go home. Health care systems' capacities to effectively mitigate COVID19 outbreaks among homeless populations is limited.

Key Facts

- Due to their vulnerability, the burden of Serious Health-related Suffering (SHS) requiring PC is high amongst the homeless population and is expected to rise during the COVID19 pandemic.
- Individuals with mental health issues who are also homeless face unique additional vulnerabilities (i.e., psychosis, cognitive decline). They also experience higher rates of physical illness, which puts them at risk of becoming seriously ill with COVID19 (1).
- PWUD are disproportionately represented among PEH and face additional risks from COVID19, linked to drug use behaviors and related healthcare needs (3).
- In many countries' PEH are highly stigmatized, despite underlying circumstances related to structural, economic, and social inequities.
- PEH have limited access to basic health and social care, including PC, medicines, and essential equipment to support patients with COVID19.
- In some countries, attention and resources have centered on the pandemic – 'bringing people in,' closing shelters and finding individual rooms. Those already identified with PC needs have been overlooked as a result. Professionals in some health and social care settings are restricted by their own organizations from visiting/supporting PEH, further compounding limited support.
- Where PEH remain on the street, their 'living' environments make it impossible to follow infection control measures such as handwashing and self-isolation.
- Hostels, where existent, may not fall under the remit of either health or social care, and this varies by country. This can complicate hostel access (especially in non-urban settings) to PPE.

Current Status

- Increasing numbers of PEH as shelter capacity is decreased due to COVID19 and clients are fearful of living in more confined quarters (1)
- Income from begging/panhandling is falling as the public is more reluctant to engage in contact - exacerbating economic vulnerability (i.e., quality/quantity of food/medications that can be purchased).
- PEH have limited access to phones/internet, compounding social isolation, and limiting ability to access help and up to date information, including public health messaging.
- Supervised consumption services for PWUD are reduced and clients may avoid accessing services to lower COVID19 exposure risk. they may be at higher risk of death from drug use in isolation¹
- Resources for health assessments of those housed in hostels/hotels are limited and maintain the invisibility of the homeless health crisis.
- Congregate living environments (i.e., shelters) render it extremely difficult to follow infection prevention and control measures, such as frequent handwashing, physical distancing, and self-isolation. Shared living facilities heighten contraction and transmission risk.
- In some countries, funds have been allocated to buy tablets for hostels/shelters/shared houses so PC coordinators can liaise more efficiently with service users and staff to provide PC support.

Recommendations

- Recognize PEH as a high-risk group for COVID19. Hospitals, primary health care and community-based services need to prioritize this population for ensuring PC support through an effective referral system.
- Integrate PC into public health systems, including public health measures being sensitive to the needs of PEH and taking a human rights approach.
- Integrate the principles of PC to the homeless into the COVID19 response i.e., flexibility, low barrier services, trusting relationships, trauma informed and person-centered care. (4)
- Estimate and plan for adequate PC support throughout the pandemic among homeless populations (i.e., segregated accommodations, staffing considerations) (5)
- Ensure PC access for individuals who are deteriorating (COVID19 and non-COVID19 related) and for whom acute care is not an option.
- Where possible provide safe accommodation options for people with nowhere to isolate “at home” (6)
- In contexts where it is not possible to do this, it is necessary to maintain access to basic sanitary supplies for both hygiene and infection prevention purposes (i.e., hand washing, masks, toilets) (7)
- Expand, rather than postpone addiction care (8), and integrate harm reduction measures into the COVID19 response to help PWUD follow public health recommendations
- Promote advanced care planning (ACP) with PEH and explore how they might want to be cared for if they become unwell (1)

- Ensure a social assessment on admission to identify whether the PEH has a family/street family and determine if connection can be facilitated.
- Recognize grief and loss during COVID19 and beyond and provide grief and bereavement support mechanisms for PEH, shelter communities, and staff supporting their care.
- Provide emotional support and PC training for people working with PEH, NGOs and FBOs caring for the PEH through PC teams.
- Enhance chaplaincy and social work collaboration to meet psychosocial, spiritual, religious, and/ or existential needs, particularly for homeless populations who may be socially isolated.
- Ensure health systems and PC teams integrate social histories upon initial assessment to evaluate economic status of individuals and families at risk for, recovering from, or currently experiencing homelessness in the context of COVID19.
- Provide a dignified burial/cremation for PEH who die ensuring those who are unidentified are treated with the utmost respect and in accordance with congruent religious/cultural practices.

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26. Risks, Challenges, and Opportunities for Fundraising during the Pandemic

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Issue:

How palliative care organizations can deliver change in a COVID world, maintaining resilience and sustainability in a context of shrinking philanthropic, health, social, foreign aid, and global health budgets.

Background

Little or no funding from Global Financial Institutions (GFI) or from national funding institutions is being allocated to civil society organizations (also referred to as NGOs) for palliative care (PC) service delivery or advocacy, per the commitments of pre-COVID multilateral agreements such as the Astana Declaration (1); the Political Declaration on Universal Health Coverage (2); WHA Resolution 67/19 (3) and WHA 73/1 (4). Long-term financial survival is key to ensuring the smooth development of PC activity, especially in the wake of the Covid-19 pandemic, the growing burden of non-communicable diseases, and the trend in ageing population. Providing for the financial sustainability and autonomy of PC organizations entails dedicated time and labor on the part of leadership, both in short supply during the pandemic. Collaborative networks at all levels, from global health governance bodies to municipalities, faith-based organizations, and civic groups, are well positioned to develop an integrated approach to PC, a service currently unavailable to the majority of the world's people.

Basic Facts

- Foundations are uniquely positioned to contribute to systems change. Without the constraints of election cycles or quarterly reports, they have the freedom to plan and act over a long-term horizon — and to take swift action when needed.
- Even before the pandemic, traditional PC funders were leaving the field, forcing PC organizations to revise strategic plans.
- The pandemic has highlighted the need for increased access to PC for vulnerable populations, particularly older persons, persons with disabilities, incarcerated, mentally ill, and homeless persons, and refugees.
- PC advocacy and service delivery are embedded in larger social, health, and financial ecosystems that can be mapped and mined for new strategic alliances.
- Sustainable advocacy and service delivery strategies in Low- and Middle-Income countries entails collaborations between private, faith based and philanthropically funded organizations serving vulnerable populations.
- Successful advocacy for PC entails partnerships between donors, governments, NGOs, and organizations working on all services in the Primary Health Care (PHC) and Universal Health Care (UHC) spectrum, particularly in resource-poor countries.
- The global PC organizations are standing by to offer advocacy training and support to national and regional PC organizations.

ⁱ Based on the presentations made by Dermott McDonald, Diederik Lohman, Faith Mwangi-Powell and Mark Mwesiga during the Palliative Care and Covid-19 series webinar.

- Finance, health, and education ministries in countries of all income levels can use these estimates to develop cost effective primary healthcare budgets that include PC.
- PC advocates in all UN member states can use the IAHP database to estimate their PC and medication needs in real time and cost them with the Essential Package.
- The World Bank, The Agency for International Development, The Global Fund, Global Financing Facility among others may entertain proposals from governments to fund integrated PC services for COVID response, HIV/AIDS, Multi-Resistant Drug Tuberculosis (MDR TB), and Non-Communicable Diseases.
- National PC associations must initiate discussions with MoH serve as consultants and collaborators in the proposal drafting and implementation.

Current Status

- National and international health system responses to COVID are excluding civil society, education, and public health actors, prioritizing security and finance.
- Most PC funders such as Open Society Foundations and the US Cancer Pain Relief fund are leaving the PC field.
- Staff redundancies are compromising charities with already limited workforces.
- Uncertainty of COVID is challenging long term planning and development of theories of change.
- Donors are repurposing funds, providing an opportunity to revive promotion of UHC that includes PC and addresses system-wide inequities that amplify vulnerabilities of populations such as older persons, persons with disabilities, refugees and migrants, incarcerated persons, and persons with PC needs.
- Restricted travel is forcing ministers, civil servants, funders, and celebrities to stay home rather than traveling out of the country for work, leisure, or medical care.

Recommendations for PC programs, associations in countries of all income levels

- Clarify the purpose and impact of your organization in a COVID world.
 - What are your values and who are your partners?
 - Refocus strategic plans, as necessary.
 - be clear and transparent about what you can and cannot do to build trust through accountability.
 - adopt a solutions-based approach that shows the urgency of PC in a COVID world.
 - be bold. Ask for unrestricted funding
 - Ask how we are involved in the changing ecosystem?
 - What role are we playing?
 - In which halls of power are we sitting?
- Develop new partnerships with other stakeholders and develop new messages and metrics relevant to the post-COVID global health landscape; link PC to broader issues such as equity and human rights; build bridges and partnerships with other actors in the ecosystem with PC as part of the ask.
- Maximize the use of online fundraising tools and crowd funding digital platforms.
- Take advantage of travel restrictions keeping funders, politicians, and celebrities at home to
 - create donor working groups and consortia.
 - identify prospective allies in other sectors.
 - build technical thought leadership profiles with funders: i.e., “we are the thought leadership for home-based care.”
- Ensure diversity and representation in your organizations.
- Enhance digital engagement.

- Identify sources and activities capable of generating funding streams to support the operational costs of the program.
 - Explore local foundations that might not have a specific interest in PC but are concerned about the health of the community.
 - Consider founding social enterprises.
- Develop indicators around QoL based on SHS
- Never give up.

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