

Palliative Care in the COVID-19 Pandemic

Briefing Note

Advocating for Integration of Palliative Care into National COVID-19 Responses: Challenges and Successes

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 COVID-19 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 COVID-19 patients and those with other forms of SHS. Although UN member states have committed – through the recent World Health Assembly (WHA) Covid-19 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 organisations need support and guidance to hold their policymakers accountable for commitments made at the international level, to integrate PC into their national COVID-19 response plans, policies, and universal health coverage strategies;
- National PC organisations 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 organisations 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 organisations 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 for national and regional PC organisations

- 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 (e.g. 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 organisations;
 - 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:
 - Familiarise themselves with existing PC guidelines and resources⁵ for Covid-19 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 Covid-19 related suffering alongside prevention and treatment⁵;
 - 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 isn't 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.

References

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