Perspective article

Palliative care in the pandemic era: Time to prioritize preparedness

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Introduction

The revised definition for Palliative care proposed by International Association for Hospice and Palliative Care emphasizes active holistic care for individuals with serious health-related suffering due to severe illness, especially those near end-of-life, and improved quality-of-life for patients, families and caregivers[1]. Global estimates reveal a huge unmet need with only 12% of the estimated 56.8 million requiring palliative care actually receiving it in a year. More than three-fourths of them reside in low-and-middle-income countries[2].Only 40% countries reported achieving coverage of atleast 50% of population eligible for palliative care[2]. A remarkable disparity has been identified in the availability and consumption of morphine for palliative care between high and low income countries, with just 1% of total manufactured morphine consumed by low and middle-income countries[2]. These disparities are bound to increase in future owing to population ageing and mounting burden of non-communicable diseases such as cardiovascular diseases, cancer and chronic respiratory diseases[2]. Against this background, COVID-19 pandemic and the consequent prevention and control measures has ushered dynamic shifts in the need, delivery and quality of palliative care.

Complexity of COVID pandemic

The redirection of health resources to pandemic management has resulted in an acute strain on palliative care services causing delay or discontinuation of care for existing patients[3]. COVID-19 with its varied presentations and unprecedented spread has underscored the necessity of palliative care at multiple settings to alleviate physical distress such as breathlessness, psychological distress of isolation and separation from families and spiritual distress associated with acute, unpredictable course of disease and mortality[2,4]. The abrupt, unexpected burden on health system draws attention to the need for palliative care training for all health professionals[2,4]. Besides the increased demand on healthcare resources, the need for COVID-appropriate behaviour, enforced isolations and long-term stringent infection control measures, calls for a new, pragmatic approach to palliative care which focuses on preparedness[5]. The pandemic has created four main categories of population in need of palliative care- those with malignancy who need continued care; population with non-malignant diseases with increased susceptibility to COVID; those with severe COVID and its complications or subsequent long COVID syndrome; the families and caregivers of patients[5]. In addition, the overworked health professionals constitute a unique vulnerable population at high risk of physical, mental, psychological and social distress.[5]Paladino et al in their reflections on the Ebola virus outbreak, outline the resultant outbreak-associated disruptions on existing health systems along with the invisible epidemic of post-traumatic stress among health providers and survivors[6].

Challenges in access and delivery of palliative care in the pandemic context[3]

Patient perspective[3]	Fear of acquiring infection[3] Fear of separation from family[3] Fear of dying alone[3] Concerns over pain and dignity in death[3] Anxiety over management decisions[3] Transportation to healthcare amidst lockdowns[7] Disruption in access to medicines and essentials due to pandemic and lockdown[7]
Provider's perspective[3]	Fear of acquiring infection from patients and families[3] Fear of transmitting infection to their own families[3] Increased burden of work[3] Limited availability of personal protective equipments (PPE) and other protective measures[3] Lack of shared decision-making[3] Psychological burden of managing terminal patients in isolation[3] Anxiety over dealing with family with regard to decision-making[3] Ethical concerns related to justifiable resource allocation[3]
Family's perspective[3]	Fear of acquiring infection from healthcare providers[3] Fear of losing loved ones in isolation[3] Anxiety over isolation measures[3] Anxiety over treatment decisions made by doctors[3] Travel to health care in the midst of restrictions[7] Economic disruptions in family[3,7]
Health System perspective[3]	Competition for reduced resources[3] Understaffing in palliative care due to redirected health cadre towards COVID care[3] Supply chain disruptions in palliative care medications due to lockdowns[3] Delay or denial in admissions due to patient overload in hospitals[3]

The way forward

Palliative care is a human right and a moral imperative of all health systems and the pandemic has exposed the inadequacy of the country states to protect this basic right for those in need.[2] To address the palliative care concerns in an unpredictable future, preparedness and sustained mitigation is the need of the hour.

For sustained mitigation efforts, Pallicovid Kerala, the taskforce in palliative care identifies five important domains of palliative care in the context of pandemic: triage with staff trained in goals of care and decision making; symptom control with uninterrupted supply of essential medicines; management of distress with provision of psychosocial, spiritual &

bereavement support; end-of-life care with health personnel trained in symptom management and communication and psychosocial support; and compassionate care and support to health care worker to avoid burnout.[8] All clinicians should be trained in identifying patients in need of various stages of palliative care at triage and appropriate referral.[3] There is a vital need for ongoing identification and approval of hospitals or health centres to provide decentralised palliative care, wards to provide end-of-life care to patients and community-based initiatives to provide grief and bereavement support to families.[3] It is the responsibility of the health system managers to equip health-care workers with knowledge on standard protocols for symptom management and guidelines to implement them in pandemic context, ensure adequate provision of PPE, vaccination and anti-viral prophylaxis for health-care workers; medications and equipments for patients; and provide tele-consultation support to establish continuum of care.[3,9]

Preparedness is done in advance in the inter-pandemic period as a measured, transparent consultative process, involving all stakeholders- potential consumers from community, clinicians, health system managers, politicians, in partnership with ethicists and experts.[10] A committed leadership, empowered communities and a supportive policy environment could assist health system in rational decision-making.[2] Preparedness should include integration of palliative care into health system at all levels; capacity-building by training and certification of clinicians, general practitioners and other frontline health personnel working under healthcare and community settings; coordination with non-governmental organizations, social and spiritual representatives.[3] The preparedness phase could be used to implement and validate the utility of telemedicine and strengthen the services in provision of palliative care.[7,10] Country-specific, standard guidelines or recommendations for tele-consultation in palliative care should be framed with specific emphasis on documentation and consideration for cultural, social, spiritual, ethical and legal contexts.[7] Effective tele-consultation services can allay anxiety and fears and serve as a source of support during the COVID-19 pandemic.[7,10]

Involvement of volunteer networks and general practitioners as essential links between specialist care and community could help ease the burden on the health care resources[7]. Family physicians and community nurses could be trained with knowledge and skills to identify and address psychological and spiritual concerns apart from physiological conditions.[7] The unusual and often chaotic scenario of a pandemic reinforces the need for promoting Advance Care planning with open discussion and documentation, early in the course of the disease to reduce emergency hospital visits, inappropriate interventions and psychological suffering for patients and families.[7,10]

Constitution and empowerment of hospital triage committees to support ethical decision-making and organisational support with holistic care for health care workers to reduce burnout are integral to the preparedness plan to ensure provision of quality palliative care.[10] In addition, integration of palliative care practice in medical curriculum and ongoing research with sharing of knowledge is essential to achieving optimal palliative care.[2]

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