

# 'Flattening' one curve: what about 'raising the line' on the other? COVID-19 and palliative care in low-income and middle-income countries

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The death toll from the COVID-19 pandemic has exposed the public to the reality of death and dying, raising awareness of the fragility of one's mortality. It has revealed to many care professionals and policy-makers the need for integrated, comprehensive care provision across public health and medical services, including palliative and end-of-life care. With large disparities in the capacity of health systems globally prior to the pandemic, inequity in the response to COVID-19-related palliative care needs was inevitable across low-income, middle-income and high-income countries (HICs). Importantly, the immediacy of the dialogue around COVID-19 response preparedness has largely muted calls around the need to enhance palliative care service provision in low-income and middle-income countries

(LMICs), and the longer term development necessary to inform future disease outbreaks specifically and the needs of the dying generally.

Palliative care (PC) was initially deprioritised in the contagion compared with efforts aimed at curbing the infection, medical management and vaccine development. However, escalating admissions to HICs intensive care units increased awareness of the prevalence of patient symptoms that can be highly distressing, including breathlessness, pain and delirium. They also highlighted the often poor quality of dying and death of those affected by COVID-19, and the grieving needs of bereaved families and friends, colleagues and communities, challenging the feasibility of individualistic Western conceptions of a 'good death'.<sup>1</sup>

Recognition of the importance of PC accordingly grew, clinical narratives emphasised the integration of care and relief for those destined not to survive, as well as saving those who could. Subsequent guidance has been provided internationally to governments to ensure continued access to controlled medicines, including opioids, during the pandemic,<sup>2</sup> alongside the need to integrate palliative care in response preparedness plans.<sup>3</sup> The COVID-19 response in HICs reinforced the vital contribution PC can make in addressing

the multidimensional needs of patients with advanced disease—for example, controlling their symptoms, augmenting their quality of life, assisting with complex decision-making and providing holistic care of physical, psychological, social and spiritual pain—shifting resources to communities, and ensuring some dignity in the dying process. For families and caregivers, too, palliating challenging bereavement grief in the short-term, and prolonged, problematic grief in the longer term, has been identified as especially important.<sup>2</sup>

Flattening the infectivity curve, to slow the spread of the virus and protect the capacity of private and public health systems, is an established public health strategy now integrated into everyday COVID-19 discourse. Less familiar in common parlance is the phrase, and complementary approach, of 'raising the line', enhancing a system's capacity to address the needs of large patient numbers. Raising the line has rarely been addressed in ongoing palliative care discussions of response preparedness, especially in LMICs. Of equal importance should be ensuring integration of PC in a response while increasing, at the operational level, the capacity of PC services to address needs of patients with advanced disease and their families.

The number of cases of COVID-19 continues to grow in LMICs, generating concerns regarding the ability of suboptimal disease surveillance systems to detect, limited laboratory infrastructure to diagnose, and often fragile health systems to cope with, the pandemic.<sup>4</sup> These countries contain two-thirds of the global population aged 60 years and above; a potential determinant of heightened viral vulnerability. Of the 90.3 m COVID-19 global cases as of 13 January 2021, India reported 10.5 m while, in Latin America, Brazil accounted for 8.1 m and Colombia, Mexico, Peru for over 1 m each.<sup>5</sup> For the latter region, already an endemic region for other zoonotic infections,

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COVID-19 feeds into a ‘syndemic’,<sup>6</sup> with complex interactions between social and environmental factors enhancing the negative effects of disease interaction. While comparatively low globally (2.2 m cases), African (especially sub-Saharan African) countries remain a concern<sup>7</sup> despite lower than projected mortality modelled using limited data during the early stages of the pandemic.<sup>8</sup>

Comparing current levels of country service development to address resulting PC need, Brazil has only ‘generalised provision,’ India ‘isolated provision’—with a disproportionate focus on the state of Kerala—and 38 African countries have ‘isolated provision’ or below, with 10 having ‘no known PC activity.’<sup>9</sup> Moreover, while some countries, like Colombia, are classified as ‘generalised provision,’ evidence shows regional inequity in service provision and availability of, and access to, opioids.<sup>10</sup> Care for the dying and bereaved is consequently lacking, with support for the grieving process reliant on families’ and communities’ emotional and physical resources already strained by familial needs from HIV, cancer and other non-communicable diseases.

COVID-19 has not only exposed what Marmot and Allen called ‘(gradient) fault lines in society and amplifie(d its) inequalities’ (p881),<sup>11</sup> it has again crudely underscored global fissures *between* HIC and LMIC settings. The COVID-19 death is not the great leveller; that myth has been exploded by everyday reality. Infectious disease outbreaks have a propensity to unveil existing societal prejudices.<sup>12</sup> Where research exists, only from HIC settings, the pandemic has cruelly shown that the infected have been affected by prior malign, structural ills, with racism, prejudice and discrimination deeply embedded in social, political and economic structures.<sup>13</sup> The extent to which this scenario is playing out, and exerting an impact, in LMICs is less known, but we know

pre-existing vulnerabilities exist due to inequalities and inequities—including unemployment, hunger and malnutrition—that can impact on access to healthcare, treatments and vaccines, and worsen in times of disease outbreaks.<sup>14</sup>

Prior to the pandemic, healthcare provision in LMICs was characterised by inadequate medication availability and shortages of healthcare providers working with scarce resources. COVID-19 has imposed additional pressures on these services. In Ghana, health systems already faced inadequate numbers of skilled healthcare professionals and essential material resources for delivery of cancer care. COVID-19 produced delays in scheduling cancer treatments, where most patients are already presenting with advanced disease. It also increased financial toxicity and treatment abandonment (with many patients relying on extended family income to support treatment costs), and restricted access to cancer facilities, potentially diverting patients towards unorthodox health practices.<sup>15</sup> Where available, cancer care in Ghana is being delivered by an already limited workforce and oncology departments that are not considered as having frontline workers, forced to operate without access to testing for COVID-19 or sufficient personal protective equipment. PC provision to patients without COVID-19 is also affected, with home visits suspended, the number of clinics reduced and appointments considerably delayed. Moreover, unknown to date is the impact of the virus on vulnerable populations in LMICs, including imprisoned populations, the homeless, migrants and ethnic groups, often marginalised, with low health literacy, limited access to healthcare services, and living in extreme poverty.<sup>15</sup>

In such LMIC countries, raising the line—in terms of building health system capacity by investing in equipment, staff (including approaches to palliative care training and curricula

development), and opioids’ and other essential medicines’ availability, delivery platforms, and awareness programmes—for the PC sector is essential. A substantive investment would not only start addressing the real, unmet and often-ignored needs of patients and families with life-limiting diagnoses, but also position health systems to better address future pandemics necessitating PC interventions. Lessons from the COVID-19 pandemic in Africa show the importance of private sector input for strengthening health system responses. A coalition of businesses (called the Africa Investment Forum: <https://bit.ly/3hpTY8l>) donated US\$3.79 billion to strengthen health systems’ capacity to address the impacts of the virus on the continent. Orchestrating long-term private sector investment in health systems strengthening, including PC, is critical to sustain efforts at raising the line for a response to communicable and non-communicable diseases.

Attempts to integrate PC may contribute to wider health systems strengthening. In doing so, it is pertinent to prioritise the development of new and existing equitable and sustainable international partnerships,<sup>11</sup> creating a pathway to determine what, how, when, for whom and with whom investment and integration can translate into positive outcomes for patients and their caregivers. It is also necessary, and aligned to the recent ranking of PC in global health research priorities arising from COVID-19,<sup>16</sup> to strengthen capacity to research health services and wider systemic factors that shape access to PC, and design strategies (including development of curricula and training of health workers)<sup>17</sup> to promote equitable access to quality PC and end-of-life care.

COVID-19 has awakened the world to the potential deadly impact of future pandemics. While ‘raising the line’ to better combat the impact of COVID-19 as a supplement to flattening the curve is important across all settings, it is imperative in LMICs,

where the need for serious investment in PC capacity and geographical coverage to meet the needs of the dying and their families remains challenging. This PC development must be advocated for and integrated into LMIC health systems, to inform responses to future disease outbreaks while striving to increase access to PC and relief of suffering for all people with advanced disease and their loved ones.

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