The Status of Palliative Care in the Asia-Pacific Region

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Sadly, palliative care remains seriously underdeveloped globally.[1,2] To set out something of the scale of unmet needs, it is estimated that 45% of the 56.2 million people who died in 2015 worldwide would have benefited from palliative care. In addition, 35.5 million of those who did not die in 2015 experienced serious health-related suffering (SHS) and would also have benefited from palliative care.[3] Yet no palliative care exists in 75 of the world’s 234 countries, and in a clear sign of global inequality, 80% of people who died with SHS were from developing regions where the vast majority are unable to access the most basic palliative care or pain relief.[3] Only 20 (8.5%) countries, most of which enjoy higher economic development, have achieved integration of palliative care into health care to an advanced level.[2] This is evident in the Asia-Pacific region where 6 of the region’s countries with higher income levels ranked in the top 20 in the 2015 Quality of Death report.[1]

From this very low baseline, the global community faces an increasing need for palliative care due to ageing populations and increasing health burden arising from noncommunicable diseases which now account for 60% of the global disease burden and 70% of deaths.[3] At the other end of the age spectrum, the needs of children are often neglected, but there are many other groups which remain hidden from view, such as people with dementia and/or living in residential aged care, the homeless, refugees, and populations caught in humanitarian crises of natural or man-made origins, and those living in remote and rural areas. And we continue to see people presenting very late to medical services in low- and middle-income countries (LMICs), with advanced incurable illness, who are then engulfed in the cycle of self-funded, financially crippling investigation and treatments, without concurrent symptomatic, palliative measures being provided. Social changes such as a more nuclear family structure, urbanization, and the increasing dispersal of family members also impact on the availability of and support for caregivers.

In the face of these and many other similar statistics pointing to gross inequality, injustice, and suffering, it would be easy to lose heart. Certainly, it makes one wonder about the intransigence and failure to address these inequalities...
with the sense of compassion and urgency they deserve. The low cost of alleviating this suffering and therefore low profit for the financially motivated may unfortunately be one disincentive to action.[3]

To lift the spirit of this editorial from one of despond to one of perseverance and motivation, we might turn to the WHO 67th World Health Assembly who in 2014, voted in support of strengthening palliative care as a component of integrated treatment throughout the life course and recommended that evidence-based, cost-effective, and equitable palliative care services be universally available. However, despite the global crisis of unmet need, palliative care was not incorporated into the 2015 United Nations 17 sustainable development goals (SDGs) which replaced the millennium development goals. Goal 3, the SDG related to health provision, set a target to achieve universal health coverage (UHC) by 2030. The definition of UHC does include avoidance of financial impoverishment due to catastrophic health-care expenses and access to quality essential health services and effective medications. Hence, it is fitting that the global palliative care community has been advocating for stronger recognition of palliative care within the concept of UHC.[4]

In 2017, the theme for World Hospice and Palliative Care day was “UHC and Palliative Care-Don't leave those suffering behind.”

Integration of palliative care in higher income countries is improving, with increased recognition of the benefits, most notably in terms of improved quality of life for patients and families and better outcomes in bereavement. However, development has been slow. LMICs in the Asia-Pacific might learn from the mistakes of others and avoid the centralization of end-of-life care in hospitals. Focusing resources on strengthening the community capacity to care for the dying is vital, but without a firm foundation of a reliable supply of opioids and trained health workers dedicated to palliative care, it will be difficult to develop and integrate palliative care.

As already noted, the global distribution of opioids is highly inequitable, with 15% of the world’s population accounting for 95% of worldwide use.[3] Opioid use remains very low in much of Southeast Asia and Oceania.[5] Fear of addiction and fear of diversion are major impediments to access but cultural attitudes toward treatment of pain, fear of criminal prosecution, and onerous regulatory processes for prescription and dispensing of opioids are also obstacles. The International Narcotics Control Board has been attempting to correct the imbalance between adequate provision and adequate protection against diversion and other forms of misuse of narcotics, but the lack of progress suggests that their message is not being heard. India illustrates the complexity of achieving this balance. Despite the historic amendment to the Narcotic Drugs and Psychotropic Substances Act in 2014, very few states have brought their processes into line with the simplified regulations, and opioid distribution only meets an estimated 4% of need or 43 mg per patient. Compare this to the distribution in western Europe which is over 18,000 mg per patient in need of palliative care.[3]

The need of the hour is for education and training in palliative care on a scale not previously achieved. There are diverse and complementary approaches to the more traditional or comprehensive institutional-, university-, or college-based education which are often too expensive for professionals living and working in LMICs. Free online courses such as e-cancer’s palliative care e-learning course for health professionals in Africa, Stanford’s Palliative Care Always program, and the relatively low-cost Education in Palliative and End-of-life care distance learning course are accessible to the global community of practitioners. Mentorship projects such as Project Hamrahi, a collaboration between Pallium India and Australasian Palliative Link International, reduce isolation and facilitate sharing of experience and expertise. The Palliative Care-Promoting Access and International Cancer Experience (PAICE) is a new quality improvement collaboration sponsored and coordinated by Stanford’s palliative care program, drawing on Stanford's Clinical Excellence Leadership Training (CELT) program, and aims to develop quality improvement skills and increase access to palliative care in India. Intensive in-country training of trainers programs, such as that developed by the Lien Collaborative for Palliative Care in Myanmar, Bangladesh and Sri Lanka, encourage multidisciplinary education and integration of palliative care into oncology and other aspects of health care. Project Echo, originally developed in New Mexico, USA, has now been introduced to India for palliative care education and development of care management expertise. The International Palliative Medicine Fellowship program is another innovation which successfully influenced palliative care development globally. International peak bodies such as International Association of Hospice and Palliative Care, the Asia Pacific Hospice Palliative Care Network, and the European Association of Palliative Care also play a major role in fostering palliative care through provision of free resources, scholarships, fellowship and providing collaborative and interactive platforms for members.

There are encouraging developments in the region. There has been a flourishing of palliative care in Sri Lanka over the past 5 years, a country previously hampered by civil unrest, natural disasters, and poverty. In Bangladesh,
the Center for Palliative Care, Bangabandhu Sheikh Mujib Medical University, has developed an urban slum project in collaboration with World Hospice and Palliative Care Alliance, which aims to relieve the suffering of older people living in two major slum districts in Dhaka. In another important development, the palliative care needs of victims of humanitarian crises have been recognized by the Sphere project. A palliative care standard has been included in the redraft of their highly influential handbook, Humanitarian Charter, and Minimum Standards in Humanitarian response, for the first time since it was established in 1997.

In conclusion, while we have not been successful in meeting the global challenge of the relief of suffering at the end of life, progress is being made slowly. Key elements for good quality care have been identified.\textsuperscript{[1,3]} Linking into the United Nations’ goal of UHC by 2030 offers a new opportunity to advocate for palliative care and specifically for implementation of the low-cost essential package of palliative care consisting of medicines, equipment, and accompanying human resources. Funding this for all families at risk of catastrophic financial ruin related to health-care needs should be an imperative for the global community, as the cost is dwarfed by the benefits possible.\textsuperscript{[3]}

Finally, it is easy to become immersed in a sense of failure when faced with this enormous challenge. When our hands are empty and our hearts heavy, reach out to colleagues, be kind to ourselves, turn to the joy and the beauty to be found in the simplicity of a smile, an act of kindness, a song or a sunrise, reconnect and persevere together.

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