Concept Note
Palliative Care and the 2030 Agenda for Sustainable Development
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The Problem — lack of palliative care in the context of population ageing and NCDs

Rapidly ageing populations as people everywhere live longer mean increasing numbers of frail elderly needing care. Likewise, the increase of chronic and non-communicable diseases (NCDs), in addition to the persistence of communicable diseases such as HIV/AIDS and tuberculosis, drive the need for publicly provided palliative care.[1] Between 2015 and 2050, the population of persons aged 60 years or older is projected to more than double, while those aged 80 years or older is projected to triple.[2] Between 2015 and 2030, the fastest population growth is expected in Latin America, the Caribbean, Asia, and Africa. In 2015, NCDs accounted for 60% of the global disease burden (in disability-adjusted life-years), compared with 43% in 1990.

More than 70% of deaths in 2015 were attributable to NCDs, and more than 75% of these deaths occurred in Lower Middle Income Countries (LMICs).[3] NCDs such as cancer, dementia, cerebrovascular disease, and lung disease cause a large proportion of Serious Health Related Suffering (SHS). They are expected to cause increasing SHS as LMICs undergo epidemiological transition. Lack of palliative care for patients and families experiencing SHS is a risk factor for stress-induced NCDs in caregivers/survivors.

The global movement to achieve UHC, and SDG3, which focuses on ensuring healthy lives and wellbeing for all people and at all ages, provides new opportunities to expand access to palliative care at a time when need is increasing rapidly.

Publicly funded palliative care services integrated into primary care under Universal Health Coverage, an objective under Target 3.8 of the Sustainable Development Goals (SDGs), is both ethical and sustainable, a win-win budget combination. Publicly provided palliative care aligns with the 2030 Agenda, adopted by all UN member states in 2015, and offers a "best buy" for member states. According to the October 2017 Lancet Commission Report, "Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage," most governments, including in the LMICs, can afford to make that choice and provide what has been defined as an "essential package" of palliative care to address SHS.

How can publicly provided palliative care under Universal Health Coverage support progress towards Agenda 2030?

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[1] The Economist. The new old. A blessing not a burden: the joys of living to 100. *The Economist*. July 6, 2017; Beaglehole, R, Bonita, R, Horton, R et al. Priority actions for the non-communicable disease crisis. *Lancet*. 2011; **377**: 1438–1447

[2] Department of Economic and Social Affairs Population Division. World population ageing 2015. United Nations, New York, NY; 2015

[3] Institute for Health Metrics and Evaluation (IHME). GBD Compare Data Visualization. IHME, University of Washington, Seattle, WA; 2016

Development experts agree that impoverished, unhealthy populations are a brake on sustainable development. To remove that brake, they formulated Target 3.8 of SDG Goal 3: 'Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all'. The World Health Organization (WHO) definition of Universal Health Coverage (UHC) includes 'palliative care' as an 'essential health service'. The safe, effective, quality, and affordable essential medicines needed for palliative care include internationally controlled medications such as morphine, unavailable in more than 80% of the world.

Improving availability of internationally controlled medicines such as oral morphine for the relief of severe pain and breathlessness, aligns with the Outcome Document of the United Nations General Assembly Special Session on the World Drug Problem, as well as with the opinio juris of several human rights experts including the Special Rapporteurs for Health, and the Special Rapporteur for the the Right to be Free from Torture. Internationally controlled essential medicines, which fall under Target 3.8, are the cornerstones of palliative care.

Publicly provided palliative care helps end poverty (Goal One)

Provided at the community level, palliative care (which represents a small *upstream* public health investment) reduces catastrophic out-of-pocket medical expenses to the family, *and* institutional costs (downstream spend) to the government and health services. In many countries, where patients present too late for curative treatment to be beneficial, scarce household and public sector resources that might otherwise be spent on ineffective or inappropriate treatments and medications are better spent on appropriate pain relief and psychosocial services that improve patients' quality of life, and in many cases allow them to return to income generating activities for their household.[4]

This low cost upstream investment helps households avoid what health economists call 'the medical poverty trap'. Furthermore, when the household breadwinner loses the ability to provide income due to serious illness or caregiving burdens, families are often unable to work, buy food, farm their land, and meet the cost of school fees. Many have to sell lands and other resources to pay catastrophic out of pocket medical expenses, further escalating hunger, malnutrition, and intergenerational poverty.[5]

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[4] Kundu, Tapas, E. Reitschuler-Cross, and Linda Emanuel. "Alleviating poverty: A proposal to mitigate the economic cost of disease." John & Gwen Smart Symposium, Chicago, IL.; Emanuel, Natalia, et al. "Economic impact of terminal illness and the willingness to change it." Journal of palliative medicine 13.8 (2010): 941-944. See also "Two hours by wooden boat, ten miles of hair-pin bends. What it takes to get to one of Malawi's most remote hospitals." http://www.heraldscotland.com/news/15778000.Two_hours_by_wooden_boat__ten_miles_of_hair_pin_bends__What_it_takes_to_get_to_one_of_Malawi__39_s_most_remote_hospitals_/

[5] Alcaraz, Carlo, et al. "The effect of publicly provided health insurance on education outcomes in Mexico." The World Bank Economic Review 30.Supplement_1 (2017): S145-S156; Ratcliff, C., Thyle, A., Duomai, S., & Manak, M. (2017). Poverty reduction in India through palliative care: A pilot project. *Indian journal of palliative care*, *23*(1), 41 https://www.ncbi.nlm.nih.gov/pubmed/28216861; see also "In Malawi,

Filling the 80% public health palliative care gap with all deliberate speed, particularly in low and middle income countries, could give an extraordinary boost both to the world's material and spiritual economies. Seeing investment in health services as an investment in development rather than as a cost, places persons, and the common good, at the center of policies, ensuring that no-one is left behind.

Goals Two (Zero Hunger) Three (Better Health) and Four (Education) Five (Gender Equality and Empowerment) and Six (Decent Work)

Meeting the caregiver deficit is just one example of how investment in the palliative care workforce can grow national economies. In 2015, the International Labor Organisation estimated a massive shortfall (3.6 million globally) in the number of workers needed to staff care homes for growing populations of older persons in all countries.[6] This number refers only to care workers, a fraction of the palliative care workforce, which is multi-disciplinary.

Countries that are serious about achieving the SDGs will invest in the wellbeing of the millions of unpaid (mostly female) family caregivers by providing them with a basic income and training in essential caregiving skills. This would support those who leave jobs or school to look after a terminally ill loved one (removing at least two people — the patient and caregiver — from the workforce). Employers will ensure that those want to stay in their jobs, or return once the caregiving is over, can access this option. Costa Rica, with its "*Ley de Cuidadores"* is the only country with such a system at the moment.

Supporting family caregivers through subsidies and training will give millions of newly "employed" adults the skills they need to carry out the essential work of tending to a very sick, very fragile family member. It represents upstream public health prevention of stress induced non-communicable diseases such as cancer, diabetes, substance use disorder, and heart disease. It provides them with disposable income to spend on basic needs, and, in many cases for payment of school fees, which are forfeit when family breadwinners lose employment due to illness.

The wherewithal to pay school fees (saved by Universal Health Coverage and removal of household need to pay OOP expenses) ensures that the next generation will be educated, instead of having to drop out of school because families are spending scarce resources on what are often futile medications and treatments. Family subsidies and community palliative care provision that enables family caregivers to return to work, help households avoid the "health poverty" trap.

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when you get cancer that is it, you are finished' Nurse tells of struggle as Scots charity donates to rural hospital" https://www.dailyrecord.co.uk/news/uk-world-news/in-malawi-you-cancer-it-11718062; Citation: Onah MN, Govender V (2014) Out-of-Pocket Payments, Health Care Access and Utilisation in South-Eastern Nigeria: A Gender Perspective. PLoS ONE 9(4): e93887. https://doi.org/10.1371/journal.pone.0093887; Whitehead, M., Dahlgren, G., & Evans, T. (2001). Equity and health sector reforms: can low-income countries escape the medical poverty trap?. The Lancet, 358(9284), 833-836.

[6] LTC protection for older persons: A review of coverage deficits in 46 countries . http://www.ilo.org/global/about-the-ilo/newsroom/news/WCMS_406984/lang--en/index.htm

By ensuring appropriate access to palliative care for all community members it invests not only in their ability to return to work but is also a public investment in workforce training that strengthens public health systems with appropriately credentialed doctors, nurses, pharmacists, social workers, bereavement counsellors and chaplains. These professionals can attend to the clinical, psycho-social and spiritual needs of the millions of children, their parents, and older persons who will need palliative care. Although services will be provided mostly in the home, and in the community by primary care workers, they can also be available in outpatient clinics, hospitals, hospice units, nursing homes, and prisons as necessary.

By integrating palliative care into their newly strengthened healthcare systems, all countries will come closer to achieving at least eight of the 2030 Agenda for Sustainable Development Goals.

These interlinked goals and targets include

1) No poverty (Goal One)
2) Zero hunger (Goal Two)
3) Good health — Universal health coverage including the provision of essential services and medicines and tackling non-communicable diseases (Goal 3)
4) Quality education (Goal Four)
5) Gender equality and empowerment (Goal 5)
6) Decent work and economic growth (Goal 8)
7) Reduced inequalities (Goal 10)
8) Responsible consumption and production — of medicines (Goal 12)