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Submission to OEWGA14

Guiding question: normative content related to right to health and access to health services.

The International Association for Hospice and Palliative Care (IAHPC)¹ is a global non-profit organization with members in more than 100 countries. As such we cannot comment on legislation in "our country." This submission reviews the global palliative care service abyss facing older persons with palliative care needs. It then lists how member states are beginning to respect, protect, and fulfill, the right to palliative care (PC) (stipulated under the right to health), with specific reference to examples of low- middle- and high-income countries that have enacted laws or policies authorizing and/or mandating service development.

Definition: Palliative care (PC) is the active holistic care of individuals across all ages with serious health-related suffering¹ due to severe illness¹¹, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.²

PC is now widely recognised as a component of the right to health for the population in general (General Comment 14, CESCR), and for older adults in particular (OAS Convention and Independent Expert).

PC is more likely to be available in countries where operational NCD policy integrates palliative care (45%) or cancer (42%) than in those without palliative care (32%) or cancer (33%) within their NCD policy.³

Need: Worldwide, only about 14% of people who need PC currently receive it (WHO). The vast majority of formal *and* unpaid informal PC caregivers are older women, who need training and basic income support. Lack of an appropriately educated health workforce, combined with unduly restrictive regulations for morphine and other essential medicines, denies 85% of people in the world with PC needs, the majority of whom are older persons, access to pain relief and PC services. (INCB and UNODC reports)

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¹ <u>www.http://www.hospicecare.com</u>

² <u>https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/</u>

³ Connor, SR. Global Atlas of Palliative Care. 2nd ed. London, UK: World Health Organization (2020)



National legislation, plans and policies

High income: The majority of European countries (76%) have adapted their General Health Laws to include PC as a mandatory service, as a right of the patient, or even as a human right. Eight countries (France, Belgium, Luxembourg, Italy, Portugal, Albania, Germany, and Armenia) have a national law. France, Belgium, and Germany reference access to PC as a right. All European countries have a national PC policy although often related to national cancer plans. Republic of Korea and Taiwan have specific laws regarding PC mostly to ensure the right of patients to choose hospice and PC, and life-sustaining treatment. Japan does not. All East Asian policies, regulations and national plans mention an explicit right to PC. In EMRO region, Saudi Arabia, Kuwait, Qatar, Lebanon, and Jordan have PC policies.

Lower- and upper middle: Argentina, Brazil, Colombia, Costa Rica, Chile, Mexico, Peru, The Philippines, Islamic Republic of Iran, Lebanon. The High Court of India ruled in March 2024 that the Indian Constitution includes PC under the right to health.

Low- and low middle-income: Botswana, Cote d'Ivoire, Ethiopia, Guinea, Kenya Libya, Malawi, Mozambique, Zimbabwe, South Africa, Swaziland, Rwanda, Tanzania and Uganda, Zambia.

Conclusion

Considering demographic changes, including increased ageing populations and the rise of noncommunicable and other chronic diseases worldwide, the need to develop and strengthen regulations and policies regarding PC and explicitly stipulating inclusion of older persons under the right to health cannot be overemphasized.

We recommend that member states:

- Collect quality data disaggregated by age and gender on morbidity and mortality of persons over 69 to assist public health departments in planning PC services for older adults in rural and urban areas. DESA projects the oldest-old will number 434 million in 2050.
- 2. Focus hospice and PC development on all patients with Serious Health Related Suffering (SHS), not only on those with cancer, which is the focus of many member state policies, including regarding prescription of controlled medicines.



- 3. Draft and enact specific laws and regulations for hospice and PC education and services, where they do not exist, in close consultation with
 - older persons and families with lived experience of serious and terminal illness
 - relevant CSOs, academia, and professional organizations, and
 - all involved government ministries *inter alia* health, social care, education, environment, housing.
- 4. Implement, and evaluate national PC plans where they are on the books but not under development, to ensure that all elements of clinical and social care are integrated into the primary health care system under Universal Health Coverage.

For promising and best practices please contact the author at <u>kpettus@iahpc.com</u>.