

International Federation on Ageing



Palliative care for older persons: a rights-based approach

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Outline of talk

- Housekeeping Definition Challenges
- Rights & instruments
- Proposed text for Convention
- Takeaway and thanks
- Normative Framework & Selected Resources

Definition of palliative care

- The active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life
- Aims to improve the quality of life of patients, their families and their caregivers.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient's illness, and in their own bereavement.
- https://hospicecare.com/what-wedo/projects/consensus-based-definition-ofpalliative-care/definition/



Former UN Independent Expert on older persons Ms. Rosa Kornfeld-Matte

"States should ensure the availability and accessibility of palliative care for all older persons in need, particularly those who suffer from a lifethreatening or life-limiting illness. Training, and adequate and affordable medication and therapeutic measures, should be provided in public and private care settings."

(Some) Challenges

- Population ageing & > chronic disease
- Poor primary health care
- Deep rooted cultural ageing and ageism
- Low palliative care 'literacy' & association with euthanasia;
- Lack of access to essential palliative care medicines
- Workforce deficits
- Nursing homes
- No binding instrument to hold member states accountable

Global Burden of Chronic Disease & PC need

- > 56.8 m people worldwide need palliative care annually
 - 25.7 million EOL care
 - 67.1% > 50 +.
- PC need re population aging & disability
- Cancer, neurodegenerative, cardiovascular, respiratory diseases and other chronic NCDs including Alzheimer's Disease

Gender & Age Intersectionality of Rights – underserved populations

- Older persons, especially older women, are disproportionally likely to experience poverty;
- OP have limited access to affordable healthcare, including palliative care, medicines, and essential equipment to support patients including with Covid-19;
- Older women comprise majority of informal caregivers;
- Older fe/male incarcerated persons/homeless/veterans
- Older LGBTQ populations
- Persons with Disabilities



Publicly provided PC for Older Persons Uruguay

Stipulated rights supporting right to PC for OP. Provision of PC supports these rights --reciprocal

RIGHTS TO

- Life, work, medical care and medicines (UDHR, CESCR)
- Highest Attainable Standard of Physical & Mental Health (CESCR)
 - General Comment 14
- Freedom from Torture, Cruel & Inhumane Treatment (CAT)
- Independent living, community participation (CRPD) & political life (ICCPR)
- Autonomy, Decision-making, Legal advice (CRPD)

Recommendations for Older Persons' Organizations

- Advocate for binding convention on rights of older persons
- Change the narrative: from "vulnerable" as a social category to "underserved" – a political category
- Create solidaristic "Compassionate Communities"
- Partner with other NGOs for advocacy at all levels of governance;
- Promote society wide advance care planning (reduces hospitalization)
- Integrate PC into PHC taking life course approach (right to health)

Suggested language for convention

Include access to palliative care in any article on the right to health

States Parties shall ensure palliative care services of good quality are available and accessible for patients and their families facing severe health related suffering.

Normative Framework – law & expert opinion

- Inter-American Convention on Rights of Older Persons
- Astana Declaration 2018 & High-Level Declaration on UHC 2019
- All Human Rights Conventions and General Comment 14
- WHA 73/1 and WHO Guidance on Clinical Treatment of COVID 19
- WHO Decade of Healthy Ageing Proposal and Report
- Statements of Independent Expert on Rights of Older Persons
- Submission of IAHPC to OEWGA9

A few resources

- Global Atlas of Palliative Care 2nd Edition 10/2020
- UN Committee on Economic, Social and Cultural Rights, "Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights," General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4
- Submission of IAHPC to OEWGA9
- Policy Brief on PC for Older Persons in COVID-19 May 2020
- Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, A/HRC/30/43, August 13, 2015, http://tinyurl.com/o8bbbx8, paras. 85–86
- WHO <u>Guidance Clinical Management of COVID-19</u> May, 2020

THANKS & TAKEAWAYS

- Rights- and evidence-based advocacy works!
- Make new NGO friends' & build collaborative relationships with other orgs, policymakers, civil servants & opinion leaders;
- KNOW & advocate for yours' and your loved ones' rights to palliative care and pain relief.

