

# Palliative Care and Human Rights for Older Persons

Palliative care is fundamental to health and human dignity and is a basic human right. Palliative care for older persons is centered around the provision of symptom management and pain relief for chronic and life-limiting illnesses, taking into account the distinct needs and capacities related to aging. Care may be provided through inpatient facilities, community-based centers, or at home, and often requires collaboration between multiprofessional health workers across different settings. Effective palliative care for older persons involves both patient and family needs and integrates physical, psychosocial, legal, and spiritual support. The right of older people to decide about individual treatment preferences and where they receive care must be protected at all times.

## The need for older persons' palliative care is growing worldwide.

- Globally, the estimated number of people in need of palliative care at the end of life was 20.4 million in 2011. The biggest proportion, 94 percent, corresponded to adults, of which 69 percent were over 60 years old.<sup>1</sup> With demographic and epidemiological changes worldwide, the number of people over the age of 60 is expected to double by 2050.<sup>2</sup>
- The United Nations' common usage of the term older person refers to individuals aged 60 years and above. However, a more comprehensive approach does not consider specific age parameters but rather understands aging as a multidimensional process that involves physical, psychological, and social changes with varying consequences and resulting in different experiences of health and well-being.
- There is a level of ambiguity on the boundaries between disability and age-related conditions. With increasing age comes increased likelihood of disability. Physical health declines with age, yet this does not necessarily mean that older persons are disabled. Disability is an evolving concept that results from the interaction between persons with impairments—including those who have long-term physical, mental, intellectual or sensory impairments—and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.<sup>3</sup>
- Patterns of disease in the last years of life are changing, with more people dying from chronic debilitating conditions, such as cardiovascular disease, obstructive pulmonary disease, diabetes, cancer, and dementia.<sup>4</sup> Since many of these often occur together among older people, this group frequently experiences multiple health problems and disabilities.<sup>5</sup>
- Dementia is estimated to affect about 4.6 million people around the world every year (one new case every seven seconds), the vast majority of whom are older persons. It is considered by the World Health Organization (WHO) a “progressive terminal illness for which there is currently no cure.” The prognosis may range from 2 to more than 15 years, the end-stage lasting as long as 2 to 3 years.<sup>6</sup> While palliative care is likely to be appropriate in end-stage dementia, it can also cause disability, particularly in its early stages.<sup>7</sup> More than 95 percent of persons with dementia need 24-hour care as the illness advances.<sup>8</sup>
- Cancer and heart failure are some of the most common diseases that cause pain and require palliative care for older persons. The prevalence of cancer increases with age and three quarters of deaths from cancer occur in patients aged over 65.<sup>9</sup> Heart failure affects more than one in ten persons aged over 70, and the five-year mortality of 80 percent is worse than for many cancers.<sup>10</sup>

- Women consistently live longer than men (six years longer on average) and nearly twice as many women than men live to 80 years of age. Older women have a higher prevalence of conditions such as dementia, osteoporosis, and arthritis, suggesting that a greater part of their “extra” survival may be impaired by these health problems.<sup>11</sup>

### Older persons have distinct and specific palliative care and end-of-life needs.

- Older persons are more commonly affected by multiple medical problems of varying severity, with intensified effects that may be much greater than any individual disease and typically lead to greater need for care. They are also at greater risk of adverse drug reactions and their illness may be superimposed on physical or mental impairment, economic hardship, and social isolation.<sup>12</sup>
- Patient surveys consistently find that pain is a predominant symptom in approximately one third of older patients.<sup>13</sup> Yet older persons tend to underreport pain, and the high prevalence of sensory and mental impairment often makes their communication more difficult.<sup>14</sup> They may also be reluctant to report pain because they expect that symptoms are a “natural” part of aging and do not believe their pain can be alleviated.<sup>15</sup>
- Older persons with dementia, for example, frequently do not receive adequate palliative care due to health care professionals not perceiving them as having a terminal condition and the difficulty in diagnosis.<sup>16</sup> They are at particular risk of poor pain control when communication services are not appropriately modified and adjusted to their needs, which often results in their pain not being well treated or even treated at all.<sup>17</sup>

“Older persons have different patterns of disease presentation than younger adults, they respond to treatments and therapies in different ways, and they frequently have complex social needs that are related to their chronic medical conditions. (...) Particular attention needs to be given to palliative care. In certain countries, this is not officially recognized as a medical specialty and the medicine used in such care is limited, for several reasons, including restrictive drug regulations, failure to implement a properly functioning supply and distribution system, and inadequate health-care system capacity.”

—UN Independent Expert on older persons (I)

- Effective ways of assessing pain among people with severe mental impairment have been developed, and although older people are generally more susceptible to adverse drug reactions, they can use analgesic and pain-modulating

medicines safely and effectively.<sup>18</sup> Opioid analgesics, such as morphine, are essential for treating the pain associated with many advanced progressive conditions.

- There is increasing research evidence concerning the decisions that people would prefer to make about care at the end of life. Studies have found that around 75 percent of respondents would prefer to die at home, although as they approach death, part of this group may come to prefer inpatient care.<sup>19</sup>
- Legal services are also an important component of older persons’ palliative care. At the end of life, patients experience emotional distress not just from physical pain. Pressing concerns can include the future of their property, access to social benefits, care of their children or grandchildren, patient confidentiality, and how much freedom they will have to choose their treatment.

“Patients come in very advanced stages. They’ve been on non-opioid pain medicines for years. The doctors have already screwed up their stomachs. They already have renal problems due to high use of non-steroidal anti-inflammatory drugs (NSAIDs)...The NSAIDs are much more dangerous than the opioids. Side effects of narcotics can be managed. We have geriatric patients who have been using NSAIDs daily for 11 to 14 months. Of course they already have intense gastrointestinal problems. They are nutritionally compromised as they are not eating because it hurts to eat.”

—Dr. Jesús Medina, Guadalajara (II)

### Respect for human rights must inform older persons’ palliative care.

- Palliative care is a recognized component of the human right to the highest attainable standard of health, which is protected in article 12 of the International Covenant on Economic, Social and Cultural Rights. According to the UN Committee on Economic, Social and Cultural Rights, states are obligated to respect the right to health and must not deny or limit equal access to preventive, curative, or palliative health services. Access to essential medicines, such as morphine, is part of the “minimum core content” of the right to the highest attainable standard of health.<sup>20</sup>
- Under Article 7 of the International Covenant on Civil and Political Rights, states are under the obligation to prevent inhuman and degrading treatment, which includes suffering from untreated pain. Two consecutive UN Special Rapporteurs on Torture and the UN Special Rapporteur on Health have stated that the denial of access to pain relief, if it causes severe pain and suffering,

may amount to cruel, inhuman or degrading treatment or punishment.<sup>21</sup> Likewise, the Independent Expert on the enjoyment of all human rights by older persons has stressed that the failure to ensure access to controlled medicines for the relief of pain and suffering is a threat to the fundamental right to health and the right to be free from cruel, inhuman, and degrading treatment.<sup>22</sup>

#### The Inter-American Convention on Older Persons (IAOP) and the Convention on the Rights of Persons with Disabilities (CRPD)

► Systems of substitute decision making which seek to supplant the autonomy of older persons with disabilities may violate **article 12 (equal recognition before the law) and article 21 (freedom of expression and opinion) of the CRPD**, as well as article 11 (right to give free and informed consent on health matters) of the IAOP.

► Obliging older persons to leave their home for treatment against their wishes if it is possible to provide them home-based care may violate **article 12 (rights of older persons receiving long-term care) of the IAOP and article 19 (independent living) of the CRPD**, which mandates that older persons have access to residential care services if they decide to remain in their home.

► Respecting older persons' right to give free and informed consent on health matters, **as per article 11 of the IAOP, requires states** to establish procedures for expressing advance wills and instructions setting out the person's values and views about care—such as place of death, an advance decision to refuse a specific medical treatment in a predefined potential future situation, or appointing a person to take decisions on their behalf in certain situations.

- The UN Committee on Economic, Social and Cultural Rights' General Comment No. 20 on Non-discrimination has highlighted that states have the obligation to ensure that all human rights are meaningful in conditions of aging and that they can be realized by older people equally and without discrimination.<sup>23</sup>
- In 2012, the United Nations Office of the High Commissioner for Human Rights recognized that the human rights system had completely overlooked various areas related to the experience of older persons, including the rights related to end of life and palliative care, particularly those arising in the delivery of home, institutional or residential care services.<sup>24</sup> Since then, this has continued to be discussed in the UN Open-Ended

Working Group on Ageing and an important development was the adoption of the Inter-American Convention on the Rights of Older Persons in 2015.<sup>25</sup>

- The 2015 Inter-American Convention on Protecting the Human Rights of Older Persons (IAOP), which is the first human rights treaty to explicitly recognize the right to palliative care, requires countries to provide access to palliative care without discrimination, to prevent unnecessary suffering and futile procedures, and to appropriately manage problems related to the fear of death.<sup>26</sup> According to the convention, older persons have the right to choose where and with whom they live, and to have access to community-based services that enable them to remain in their own home, should they so decide, and to accept or refuse health treatments (article 12). The convention also determines that states must establish a procedure that enables older persons to indicate their advance will and the future course of their health care interventions, including palliative care (article 11).<sup>27</sup>
- The Convention on the Rights of Persons with Disabilities (CRPD) defines basic principles and state obligations relevant to older persons with disabilities, such as respect for individual autonomy and decision-making, full and effective participation and inclusion in society, accessibility, and reasonable accommodation. Thus, according to the CRPD, older persons with disabilities must be enabled to access information and communication technologies and services on an equal basis with others (article 9), and be able to exercise the right to freedom of expression and opinion (article 21). They must also be able to live independently, should they so decide, choosing their place of residence and where and with whom they live, having access to in-home, residential, and other community support services (article 19).

#### International policies and standards recognize the right to palliative care for older persons.

- Two international policy instruments have guided action on aging since 2002: the Political Declaration and Madrid International Plan of Action on Ageing and the World Health Organization's Active Ageing: A Policy Framework. Both recognize that health systems should provide a continuum of care that includes and extends to the appropriate treatment of chronic health problems and effective palliative care for older persons.<sup>28, 29</sup>
- The 1991 United Nations Principles for Older Persons declares that "[o]lder persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent

or delay the onset of illness.” It also establishes that older persons should be able to enjoy “full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”<sup>30</sup>

- The Council of Europe Recommendation on the Promotion of Human Rights of Older Persons dedicates a specific title to palliative care, in which it sets out that older persons should be entitled to access palliative care “in a setting consistent with their needs and preferences, including at home and in long-term care settings.” It particularly recommends that states ensure the adequate availability and accessibility of palliative care medicines.<sup>31</sup>

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

—UN Independent Expert on older persons (III)

## Recommendations

**Without urgent and concerted efforts to make palliative care available for older persons, vast suffering will continue.**<sup>32</sup>

Governments should take the following steps:

- Develop a national palliative care strategic plan with a specific focus on the needs of older persons, particularly the need for palliative care and social care, including care that supports individual choice to live in the community.
- Ensure that older persons’ palliative care is progressively available, accessible, acceptable, and of sufficient quality for all, without discrimination, particularly supporting home-based palliative care.
- Establish legal services that enable older persons to indicate advance instructions with regard to health care interventions and express their will, including the disposition of property, and planning for children under their care.
- Eliminate unnecessary regulatory barriers that restrict availability and access to essential palliative care medicine to treat age-related chronic and non-communicable diseases, particularly opioids.

- Integrate palliative care for older persons into the curriculum and training programs of medical, nursing, and other health care professionals—with training in geriatric illnesses and oriented toward ensuring that health care provided to older persons is based on free and informed consent.

## Quotes

- (I) *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.
- (II) Human Rights Watch interview with Dr. Jesús Medina, November 16, 2011, Guadalajara (HRW 2014).
- (III) *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>, para. 87 and 131.

## Notes

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2. WHO, *World Report on Ageing and Health*, Geneva, 2015, [http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1), pp. 43–45.
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17. *Supra*, WHO Europe, *Better Palliative Care for Older People*, p. 20.
18. *Supra*, AGS, “Panel on Persistent Pain in Older Persons: The management of persistent pain in older persons.”

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### Open Society Public Health Program

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