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Committee on Social Affairs, Health and Sustainable Development

The provision of palliative care in Europe

Report¹

Committee on Social Affairs, Health and Sustainable Development

Rapporteur: Mr Rónán Mullen (Ireland, EPP/CD)

A. Draft resolution²

1. The Parliamentary Assembly recognises that palliative care is fundamental to human dignity and a component of the human right to health.
2. Building on the definition given by the World Health Organization, the Assembly notes that palliative care focuses on preventing and relieving suffering associated with a life-threatening or life-limiting condition through a holistic approach addressing physical, psychosocial and spiritual problems. The goal of palliative care is to improve patients' quality of life and that of their families, and to uphold their dignity, by alleviating suffering in all its forms.
3. Echoing its Resolution 1649 (2009) "Palliative care: a model for innovative health and social policies", the Assembly stresses that palliative care should be available not just to the terminally ill but also to those who are chronically ill and to persons requiring high levels of individual care who would benefit from the palliative care approach. With an ageing population, living longer and with more years of chronic illness and pain, a substantial increase in palliative care needs can be anticipated over the coming years.
4. The Assembly deeply regrets that fifteen years after the adoption of Committee of Ministers Recommendation Rec(2003)24 to the member states on the organisation of palliative care, hundreds of thousands of people in Europe still do not have access to appropriate palliative care services. The Assembly is particularly concerned by the lack of access to appropriate pain relief leading to situations in which patients suffer for months and even years and experience avoidably painful deaths.
5. The Assembly notes that the lack of appropriate palliative care services not only increases suffering for patients and families but also involves higher costs for the healthcare system, as it leads to unnecessary hospital admissions, as well as inappropriate recourse to expensive emergency services and treatments. Consequently, it is of utmost importance to identify palliative care needs as early as possible and to provide palliative care services at all levels of care. This should include, in particular, palliative care services at the level of community and home-based care, where such

¹Reference to Committee: Doc. 14039, Reference No. 4213 of 20 April 2016 (extended on 20.03.18).

²Draft resolution unanimously adopted by the Committee on 17 September 2018, in Lisbon, Portugal.

services can be provided at a lower cost and where people with limited access to medical facilities can be reached.

6. The Assembly pays tribute to the millions of informal caregivers - spouses, partners, relatives and friends - who provide care to loved ones suffering from a chronic illness, disability or other long-lasting health affliction. It recognises the crucial and irreplaceable role which informal caregivers play in the provision of palliative care and stresses the importance of adequately supporting these caregivers in their role. Bearing in mind that most patients prefer to stay, and eventually die, at home, the Assembly notes that the need for informal caregiving can only grow in coming years.

7. In view of the above, the Assembly calls on the Council of Europe member States to take the following measures with a view to strengthening palliative care services and to ensuring access to quality palliative care for both adults and children who need it:

7.1. to recognise palliative care as a human right, define it as part of the healthcare system, and dedicate the necessary resources to it;

7.2. to integrate palliative care into all services and settings of the healthcare system, in particular, to extend palliative-care services to all patients with life-threatening or life-limiting chronic conditions;

7.3. to ensure access to pain treatment and management as a crucial component of palliative care, in particular:

7.3.1. to remove legal and regulatory obstacles that restrict access to pain-relieving medication in the context of palliative care;

7.3.2. to address educational and attitudinal barriers by raising awareness of opioid-based treatments among healthcare professionals and the general public;

7.4. to provide comprehensive support for informal caregivers, and in particular:

7.4.1. to offer them respite services and bereavement support, and to protect them against financial losses;

7.4.2. to remove any barriers that prevent men and women from identifying, sharing, determining and playing their role in informal caregiving, having regard to their particular situation and needs;

7.5. to ensure adequate training on palliative care for healthcare professionals, in particular;

7.5.1. to include basic palliative care training in medical and nursing schools, and to ensure continuing professional education on palliative care;

7.5.2. to recognise palliative care as a medical speciality;

7.6. to systematically provide psychological, emotional and spiritual support for patients and families;

7.7. to improve public awareness of palliative care via media and information campaigns;

7.8. to take measures to foster partnership between government and civil society, in the provision of palliative care services;

7.9. to consult people living with life-threatening or life-limiting conditions, as well as their carers and health professionals, in the development of palliative care-related policies and services;

8. Finally, the Assembly invites the World Health Organization to pay particular attention to palliative care in following the implementation of target 3.8 of the Sustainable Development Goals on achieving universal health coverage.

B. Explanatory memorandum by Mr Rónán Mullen, rapporteur

“You matter because you are you and you matter until the end of your life.

We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders, founder of the modern hospice movement

1. Introduction

Prologue

At the heart of the provision of palliative care is the concept of dignity. Dignity is inherent to all human persons, and our human rights flow from our inherent dignity. Palliative care is an expression of the fact that dignity should be respected throughout a person’s life until his or her natural death. The provision of palliative care to all who suffer from chronic, debilitating and terminal illness is a means by which our society can vindicate our inherent human dignity by valuing the life of each individual human person. The values of hope and solidarity drive us to care for each other, particularly our loved ones, even in the face of great illness and suffering. “And even if we know that we cannot always guarantee healing or a cure,” said Pope Francis recently, “we can and must always care for the living, without ourselves shortening their life, but also without futilely resisting their death. This approach is reflected in palliative care [...] as it opposes what makes death most terrifying and unwelcome – pain and loneliness.”³

1.1. Procedure

1. On 21 April 2016, 24 Assembly members, including myself, tabled a motion for a resolution on “The provision of elderly and palliative care in Europe”. Referring to Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care, the motion called for an investigation into palliative care provision in Europe, with particular reference to access and resource allocation. The motion was referred to our Committee and I was appointed Rapporteur on 10

³ Message from Pope Francis to the President of the Pontifical Academy for Life ahead of the European Regional Meeting of the “World Medical Association” on “end of life” issues (16 November 2017).

October 2016. The Committee simultaneously decided to change the title of the report, excluding the term “elderly”, as issues related to older persons’ health were being covered by a separate report.⁴

2. On 24 January 2018, the Committee held a hearing with the participation of Mr Philip Larkin, Professor of Clinical Nursing on Palliative Care at University College Dublin and Our Lady's Hospice and Care Services; Ms Tiina Saarto, Professor of Palliative Medicine and Chief Physician at the palliative care centre in Helsinki University Hospital; and Mr Henri de Rohan-Chabot, Executive Director of France *Répit* Foundation.⁵ The experts stressed that palliative care was a human right. They noted that it was essential to integrate palliative care into healthcare systems and to ensure good coordination among different palliative care providers, with a view to ensuring access to quality palliative care for all, across the lifespan. The experts also emphasised that informal caregivers play a crucial role in palliative care provision and that it is important to provide appropriate support for these persons.

3. On 13-14 March 2018, I carried out a fact-finding visit to Madrid and Barcelona (Spain). In Madrid, I met, *inter alia*, representatives from the Ministry of Health, members of the Health Committee in the Spanish Congress, representatives of the Spanish Association against Cancer (AECC),⁶ the Spanish Society of Palliative Care (SECPAL)⁷ and Spanish Medical Colleges Organisation (OMC).⁸ I also visited Laguna Hospital Care Centre, a private hospital specialising in palliative care, where I spoke with patients and family members. This inspiring visit confirmed me in my conviction that, even as death approaches, patients and their families can and do experience peace and positivity when offered appropriate medical, psychosocial and spiritual support respectful of their dignity and needs. My meetings in Barcelona were hosted by the World Health Organization’s Collaboration Centre for public health palliative care programmes. Here, I had the opportunity to gather extensive information about palliative care provision in Catalonia from professionals working in the field. I should like to thank all my interlocutors for their valuable contributions, as well as the delegation of the Spanish Parliament and its Secretariat for their help in organising my visit.

1.2. Definition and scope

4. The World Health Organization (WHO) provides the most widely-used definition of palliative care, in accordance with which “palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems including physical, psychosocial and spiritual”.⁹ WHO has also developed guidelines which attempt to encourage a standardised scientific approach to the diagnosis

⁴ See Resolution 2168 (2017) on “Human rights of older persons and their comprehensive care”.

⁵ One of the main objectives of the France *Répit* Foundation is to develop respite services to support informal/family caregivers.

⁶ AECC is a non-profit organisation involving patients, families, volunteers and professionals. Its mission is to fight against cancer and lead the society’s effort to reduce the impact caused by the disease.

⁷ SECPAL is an organisation gathering professionals working in the field of palliative care, including physicians, social workers and psychologists. Its aim is to improve palliative care provision in Spain.

⁸ OMC’s mission is to represent, organise and defend the medical profession in Spain.

⁹ For references to WHO in this document, see the WHO website on palliative care.

and treatment of severe acute and chronic pain to inform the work of policymakers and healthcare professionals.¹⁰

5. Based on the WHO definition, palliative care seeks to improve patients' and their families' quality of life and to uphold their sense of dignity by focusing on the alleviation of suffering in all its forms. Palliative care focuses not only on the effective management of physical symptoms, but also addresses the emotional, psychological, spiritual, social, and economic problems associated with the patient's condition, thus helping him/her "to live as well as possible, for as long as possible".¹¹ Consequently, palliative care is about a holistic approach that meets "the needs of the whole person, not just their medical condition".¹²

6. The starting point of this report is the above-mentioned definition from WHO regarding adult palliative care¹³ which "affirms life, regards dying as a normal process and intends neither to hasten nor to postpone death".¹⁴ Children's palliative care, while closely related to adult palliative care, is a specialisation in itself and requires full consideration separately. For that reason, palliative care for children is mentioned in this report in context but the full range of relevant issues is not discussed. Euthanasia and assisted suicide are not part of palliative care practice¹⁵ and are therefore not addressed in this report. Also, the appropriate decision-making structures for medical treatments at the end of life, involving patients, families, healthcare professionals and others, are dealt with elsewhere and do not feature in significant detail here.¹⁶

7. The issue of palliative sedation deserves mention. "Sedation seeks, by means of appropriate medication, to reduce awareness to a degree which may extend to loss of consciousness. Its aim is to alleviate or remove the patient's perception of severe pain or suffering when every available treatment adapted to this situation has been offered and/or dispensed but which has failed to bring the expected relief. The aim of sedation is not, therefore, to shorten life,"¹⁷ but it can have this effect. Since the primary purpose of palliative sedation is to relieve suffering, it should not be denied to a patient by reason only of fear of hastening death. However, palliative sedation should not be used as a mask for euthanasia.

¹⁰ WHO Normative Guidelines on Pain Management (2007).

¹¹ "Too few cancer patients are getting end-of-life care", Lucy Ziegler, 6 February 2018, The Independent online.

¹² The Worldwide Hospice Palliative Care Alliance (WHPCA), World Hospice and Palliative Care Day Toolkit 2017.

¹³ Albeit closely related to adult palliative care, children's palliative care is a specialty in itself, and should be addressed separately. WHO has a separate definition for palliative care for children.

¹⁴ WHO.

¹⁵ WHPCA position paper on euthanasia and assisted dying.

¹⁶ See "The Guide on the decision-making process regarding medical treatment in end-of-life situations" drawn up by the Committee on Bioethics of the Council of Europe (DH-BIO) and Assembly Resolution 1859 and Recommendation 1993 (2012) "Protecting human rights and dignity by taking into account previously expressed wishes of patients".

¹⁷ "The Guide on the decision-making process regarding medical treatment in end-of-life situations", DH-BIO, 2014.

8. The past and present role of hospices operated by charitable, voluntary and faith-based organisations in the provision of palliative care is deserving of particular mention. In many member states, palliative care services are heavily reliant on this sector which is often a leader and innovator in policy and service development. These organisations also make a major contribution to the funding of palliative care within member states through their private fundraising efforts.

9. The work of the European Association for Palliative Care (EAPC) should be acknowledged. Its Atlas of Palliative Care in Europe provides invaluable analysis, benchmarks palliative care services across member states and should inform efforts to improve palliative care services.¹⁸

2. Evolution of palliative care

10. Historically, palliative care was geared towards the needs of a specific population (i.e. cancer patients) for a specific timeframe (i.e. at the end of life). However, it gradually became clear to political and healthcare leaders that this focus was too narrow, that many other people would stand to benefit from this kind of care¹⁹ and at a far earlier stage than the period when death was imminent. In its Resolution 1649 (2009) “Palliative care: a model for innovative health and social policies”, the Parliamentary Assembly underlined that, palliative care should be available, not just to the terminally ill, but to those who are seriously ill and chronically ill, as well as to all those requiring high levels of individual care who would benefit from the palliative care approach.

11. Today, it is widely acknowledged that palliative care should be provided to different patients, regardless of age, with a wide variety of life-threatening or life-limiting conditions that go hand-in-hand with distressing symptoms. Examples are cardiovascular diseases, diabetes, HIV/AIDS,²⁰ motor neurone disease, multiple sclerosis, Parkinson’s disease, dementia, heart, renal and liver diseases and drug-resistant tuberculosis. WHO states clearly that palliative care is applicable early in the course of an illness (i.e. not just at the end of life), in conjunction with other therapies intended to prolong life such as chemotherapy or radiation therapy.

12. WHO estimates that each year, 40 million people are in need of palliative care, the majority of whom have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). However, as indicated above, many other conditions may require palliative care. It is expected that the population requiring palliative care will grow considerably over the next decades as a result of an ageing population “living and dying with more complex conditions”.²¹

2.1. Palliative care provision for life-threatening or life-limiting diseases other than cancer

¹⁸ EAPC Atlas of Palliative Care in Europe (2013).

¹⁹ Opinion of the COMECE Working Group on ethics in research and medicine on Palliative care in the European Union, Secretariat of the Commission of the Bishops’ Conferences of the European Community, February 2016.

²⁰ Palliative care in the past had a greater role in the management of AIDS, but increasingly the focus must be on providing appropriate anti-retroviral treatment, thus obviating the need for palliative care services in this situation.

²¹ The Global Atlas of Palliative Care at the end of life, WHO, January 2014.

13. Despite these estimates, palliative care services still largely focus on cancer patients and mostly on end of life care. Consequently, many people living with other life-threatening or life-limiting conditions do not receive any palliative care or receive it only in the last phase of their illness. There is a need to move away from seeing palliative care as mainly reserved for those suffering from terminal cancer towards providing palliative care services to patients with other life-threatening or life-limiting conditions. Moreover, palliative care needs should be identified as early as possible, in the primary care setting, so as to provide for those needs in a timely manner, if necessary alongside treatments targeting the underlying disease. This concept of simultaneous disease targeting and palliative approaches to care is yet to be established, especially in areas other than cancer care.²² Limited or delayed palliative care provision not only increases suffering for patients and families but also involves higher costs for the health system, as it leads to unnecessary hospital admissions and inappropriate recourse to expensive emergency services and treatments.

14. In Spain, a majority of patients accessing palliative care services have a cancer diagnosis. However, within the context of the NECPAL (*Necesidades Paliativas*; Palliative Needs) programme,²³ palliative care researchers have developed a tool to identify non-cancer patients in need of palliative services. This programme is based on the British experience of the Gold Standards Framework and consists in the early identification of chronic patients in need of palliative care approach in conventional services.

2.2. Integration of palliative care into healthcare systems, with a focus on community and home-based care

15. According to WHO, to be sustainable and accessible, palliative care should be integrated into all services and settings of the healthcare system, including in particular community and home-based care, with appropriate support for care providers (see under point 5.2). In fact, since it is both unsustainable and undesirable that an ever-increasing number of chronically ill and dying patients would be cared for primarily in a hospital setting, countries should prioritise the provision of palliative care services in the community and at home, where such services can be provided at a lower cost and where people with limited access to medical facilities can be reached.²⁴ It should not be forgotten that most patients want treatment options which allow them to stay in their homes as long as possible, and most people would prefer to be at home when they die. Thus, there are economic, legal, moral and social arguments for investing more in services in the community and at home.

16. Catalonia in Spain is a good example of how integration of palliative care into the health-care system can save on costs. By 2012, 237 palliative care clinical services had been implemented in Catalonia, including 72 home care support teams, 49 hospital support teams, 60 units with 742 dedicated beds, 50 outpatient clinics, and six psychosocial support teams. The yearly costs were

²² "Barriers to Access to Palliative Care", Palliative Care: Research and Treatment 1-6, 20 February 2017, published online.

²³ The objective of the NECPAL programme is to guarantee quality palliative care to individuals identified as having advanced chronic illnesses.

²⁴ WHO Resolution EB134.R7 on "Strengthening of palliative care as a component of integrated treatment within the continuum of care" calls upon member states to strengthen and implement palliative-care services, with an emphasis on primary care, home care and community-based care.

around € 52 568 000, down from € 69 300 000 (with net savings to the national health system of €16 732 000).²⁵

3. Palliative care: a human right

17. The Parliamentary Assembly recognised, as early as 1976, the need “to ensure that all sick persons, whether in hospital or in their own homes, receive relief of their suffering (...)”.²⁶ In its Recommendation 1418 (1999) “Protection of the human rights and dignity of the terminally ill and the dying”, the Assembly went further and encouraged member states to recognise the right to palliative care as a “legal entitlement”. Similarly, in 2014, the United Nations (UN) acknowledged that access to palliative care is a legal obligation on the part of governments and health services, when the first WHO resolution dedicated to palliative care called on governments to ensure access to palliative care within national health systems.²⁷

18. Palliative care advocates consider, however, that palliative care is not simply a legal entitlement but a human right. In 2012, the European Association for Palliative Care, the International Association for Hospice and Palliative Care, the Worldwide Hospice Palliative Care Alliance, Human Rights Watch and the Union for International Cancer Control launched the Prague Charter, “Palliative Care: a human right”, which urged governments worldwide to focus their efforts on developing or improving palliative care by, among other things, widening patient access to pain medication.

19. There are legal arguments to support the human rights foundation of palliative care. In fact, in its General Comment No. 14 of 2000, the UN Committee on Economic, Social and Cultural Rights, the independent body charged with monitoring compliance with the International Covenant on Social and Economic Rights, stated that the right to the highest attainable standard of physical and mental health is an inclusive right that extends to “preventative, curative and palliative health services”, thus recognising palliative care as a component of the human right to health. The Committee also called for “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”.²⁸

20. Moreover, at the international level, it is increasingly recognised that the denial of palliative care, and in particular pain relief, can amount to a human rights violation. In fact, in his 2009 report focused on health care, the UN Special Rapporteur on torture, Manfred Nowak, noted that: “the de facto denial of access to pain relief, if it causes pain and suffering, constitutes cruel, inhuman or degrading treatment.” In 2013, his successor, Juan Méndez, emphasised that when states deny access to pain treatment, they “not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”²⁹ Finally, in their national law regarding palliative care provision, some countries refer to palliative care as a human right (see paragraph 25). With a

²⁵ “The Catalonia WHO demonstration project for palliative care implementation: quantitative and qualitative results at 20 years”, Gómez-Batiste, Xavier & al., Journal of pain and symptom management, January 2012.

²⁶ Recommendation 779 (1976) “Rights of the sick and dying”.

²⁷ WHO Resolution EB134.R7.

²⁸ UN Committee on Economic, Social and Cultural Rights General Comment Number 14, UN Doc E/C.12/2000/4, 11 August 2000.

²⁹ UN Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, 14 January 2009; and of Juan E. Méndez, UN Doc. A/HRC/22/53, 1 February 2013.

view to advancing palliative care provision in Europe, it would be important to strengthen recognition of access to palliative care as a human right amongst Council of Europe member states.

4. Council of Europe political leadership on palliative care

21. On 12 November 2003, the Committee of Ministers adopted Recommendation Rec(2003)24 to the member states on the organisation of palliative care. The recommendation defines palliative care as “a vital and integral part of the healthcare system and an inalienable element of a citizen’s right to health care”. It therefore considers that “it is a responsibility of the government to guarantee that palliative care is available to all who need it”.

22. The Recommendation urges countries to adopt policies, legislative and other measures with a view to building a comprehensive national policy framework for palliative care. It identifies the following core dimensions for palliative care provision: symptom control, psychological, spiritual and emotional support, support for families and support for the bereaved. Accordingly, access to palliative care, including access to adequate pain medication, should be guaranteed on the basis of need and without undue financial barriers. Informal caregivers should be supported in their caregiving, and should not incur major setbacks, such as job loss, as a consequence of their caring role. There should also be sufficient respite facilities for caregivers. Highlighting the importance of academic recognition of palliative care, the Recommendation says it should be included in all undergraduate training programmes for both doctors and nurses.

23. The Recommendation constitutes a strong political commitment from the Council of Europe member states to the development of palliative care services to the highest possible standards. Following the adoption of this instrument, the European Parliament commissioned a study in 2008: “to establish clear diagnosis on where the European Union (EU) as a whole, and every member state in particular, stand in respect to the proper definition, organisation, offering and financing of palliative care; analyse some selected examples of best practices (...) and finally, present policy options (...) to improve the present situation”.

24. The study concluded that considerable advances had been made in the field of palliative care in the previous five to ten years throughout Europe (e.g. in 2008, every EU member state had palliative care services), and noted that there were numerous national initiatives underway to further improve quality and equitable service coverage in EU member states. However, it also noted flagrant disparities in the availability and quality of, and access to, the care provided, not only between member states, but also between regions, rural and urban areas as well as among social groups. The study refers to the Committee of Ministers’ recommendation as an example of how European leadership can stimulate national advancement in palliative care.³⁰

25. A more recent study on national palliative care policies in 53 European countries within the WHO European Region (including 43 Council of Europe member states) found that 18 countries - all of which are Council of Europe member states - had a national palliative care plan or strategy. An additional 13 countries were working towards publishing national plans. Moreover, 29 countries, including 26 Council of Europe member states, had a national law regarding palliative care provision.³¹

³⁰ “Palliative Care in the European Union”, Policy Department, Economic and Scientific Policy, European Parliament, May 2008.

³¹ This includes general laws on palliative care, national and general laws on health care with reference to palliative care, specific legislation or governmental decrees relating to certain features of palliative care and legislation on end-of-life issues with references to palliative care.

The first countries to establish palliative care legislation were Hungary (1997), France (1999), Belgium and Spain (2002)³², with the last three including a reference to palliative care as a human right.

26. The study stressed that the Committee of Ministers' recommendation had marked a change in the development of palliative care policy throughout Europe coinciding with a somewhat sharp increase in the development of the discipline across the continent. While it is difficult to attribute quantifiable advances in a given field to a single set of recommendations, the study noted that the Recommendation Rec(2003)24 had articulated support for national palliative care policy at a relatively early stage of European development in the field. As such, the Council of Europe may have had a tangible influence in the improvement of the situation.³³

5. Shortcomings in palliative care provision

27. Although palliative care has long been recognised worldwide as one of the most important elements in improving the quality of life of patients approaching the end of life and of those with deteriorating infirmities, the need for palliative care and pain relief has been largely ignored in many countries. A recent Lancet Commission report explains this neglect by referencing several barriers including the focus, within medicine, on curing patients and on extension of life to the detriment of care-giving and attention to the quality of life near death;³⁴ opiophobia, i.e. prejudice and misinformation about the appropriate medical use of opioids³⁵ (e.g. belief that opioids are dangerous and should be used as little as possible); the focus on preventing non-medical use of internationally-controlled substances; limitations on patient advocacy because of the stress and difficulty of dealing with serious illness; and the global neglect of non-communicable diseases which account for much of the need for palliative care.³⁶

28. These considerations also apply to some European countries and the extent to which people have access to palliative care varies considerably across the continent. In fact, in his recent human rights commentary relating to care of older persons, the (former) Council of Europe Commissioner for Human Rights stressed that access to palliative care and pain relief remained problematic in Europe. He noted that many countries on the continent were affected by shortcomings in relation to palliative care, e.g. a lack of palliative care policies, of training in pain management for caregivers, as well as problems regarding regulation and availability of opioids.³⁷

³² In Spain, palliative care is included among the basic health benefits provided in primary and specialised care, thus guaranteeing palliative care for all Spanish citizens.

³³ "Policy on palliative care in the WHO European region: an overview of progress since the Council of Europe's (2003) Recommendation 24", *European Journal of Public Health*, Vol. 26, No.2 , 230-235.

³⁴ Similarly, the explanatory memorandum to the Assembly Resolution 1649 (2009) "Palliative care: a model for innovative health and social policies" underlines that the over-emphasis on highly sophisticated and costly curative medicine is increasingly failing to meet the basic needs of people suffering from chronic diseases.

³⁵ The current epidemic of opioid dependency in the United States of America is testimony to the danger of an inappropriate medical use of opioids. According to WHO, it is the over-prescription of opioids for chronic, non-cancer pain outside palliative care which is driving the epidemic of opioid dependency in the USA. <http://apps.who.int/medicinedocs/documents/s23194en/s23194en.pdf>, last accessed on 24 July 2018.

³⁶ "Alleviating the access abyss in palliative care and pain relief - an imperative of universal health coverage: the *Lancet* Commission report", *Lancet*, Volume 391, No. 10128, p1391–1454, 7 April 2018.

³⁷ The Commissioner for Human Rights, Human rights comment on "The right of older persons to dignity and autonomy in care", published on 18 January 2018.

5.1. Symptom control: Access to pain relief

29. Pain is one of the most common and distressing symptoms experienced by patients with life-threatening or life-limiting conditions. It has a profound impact on quality of life and can have physical, psychological and social consequences. It can lead to reduced mobility and loss of strength, compromise the immune system, and interfere with a person's ability to eat, concentrate, sleep, and interact with others. People who live with chronic pain have been found to be four times more likely to suffer from depression or anxiety than people who are not in pain. Chronic pain can also negatively influence the course of disease.³⁸ Pain control is thus a crucial component of palliative care.

30. Opioid analgesics play a vital role in the treatment of pain and other common distressing physical symptoms such as breathlessness, and WHO defines them as essential medicines. They are effective, inexpensive and easily administrable. However, in Council of Europe member states, access to medicine, notably opioids and other pain-relieving treatments, continues to be a main obstacle to meeting patients' essential needs in palliative care. In the EU, about 1.3 million people die from cancer each year. Many are in severe pain, even though effective pain medication is possible.³⁹ This is probably a conservative estimate of the unmet need for pain relief, because it neither includes patients with other chronic diseases requiring palliative care, nor does it aggregate figures from non-EU member states.

31. Human Rights Watch (HRW) has reported that about 8 000 people die from cancer in Armenia every year, many spending their last days in extreme pain. Often in these cases, when there is no longer hope of curing cancer, and treatment is ineffective, patients are sent home. Fewer than three per cent of those who need morphine in Armenia receive it because of bureaucratic barriers around prescribing and dispensing morphine (and other strong opioids).⁴⁰ Similarly, in Ukraine, tens of thousands of patients with advanced cancer suffer from severe pain every year because they cannot access pain-relief medication.⁴¹ The Commissioner for Human Rights has more recently reported that Armenia and Ukraine have made progress in this area. Armenia has adopted a national strategy to introduce palliative care services which focuses on pain relief and the improvement of quality of life for people with life-threatening illnesses. It has also registered two forms of liquid oral morphine, paving the way for their use in the public health-care system.

32. The "Access To Opioid Medication in Europe" (ATOME) project investigated why opioid medicines effective in treating moderate to severe pain as well as opioid dependence itself were not used adequately in twelve European countries,⁴² and developed customised solutions for improved access to opioid medicines in these countries. The report found major barriers in the field of legislation (for example overly strict regulations restricting permission to prescribe opioids to physicians of certain specialities or who hold a special licence), national policies, knowledge and societal attitudes, and economic aspects such as affordability.

33. The key recommendations towards overcoming those barriers involved the inclusion of treatment with opioids (knowledge, skills, and attitudes) in undergraduate and postgraduate education for relevant healthcare professionals (primarily physicians, nurses, and pharmacists); raising awareness of treatment with opioids among practicing healthcare professionals (for example, via continuing medical education, publications about the rational and beneficial use of opioids in highly-

³⁸ "Building integrated palliative care programs and services", edited by Xavier Goméz-Batiste and Stephen Connor, p. 193.

³⁹ Access To Opioid Medication in Europe, Final report and recommendations to the Ministries of Health, 2014.

⁴⁰ "Armenia has a new strategy to help the terminally ill", Human Rights Watch, 12 October 2017.

⁴¹ "Uncontrolled Pain: Ukraine's obligation to ensure evidence-based palliative care", Human Rights Watch, May 2011.

⁴² Bulgaria, Cyprus, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Serbia, Slovakia, Slovenia and Turkey.

accessed national medical journals); and raising awareness among the general public via media or information campaigns and brochures for patients and their relatives.⁴³

5.2. Support for family-based and other informal caregivers

34. Support for informal caregivers with a view to improving their quality of life and well-being, as well as helping to ensure that they are able to care for their loved ones, is a core aspect of palliative care provision. Caregivers need support with the organisation of care, in dealing with the emotional burden caused by their loved one's illness and with the actual work of care, and they will need bereavement support after the death of the patient.⁴⁴

35. Today, it is estimated that there are more than 100 million carers within the EU who provide care to someone with a chronic illness, disability or other long-lasting health or care need.⁴⁵ These informal/family caregivers - spouses, partners, relatives and friends - play a crucial and irreplaceable role in the provision of palliative care. Against the background of an ageing population and given the widespread expression of preference for care at home, their role can only grow in the coming years.

36. During the expert hearing in January 2018, Mr de Rohan-Chabot stressed that home-based palliative care services were often oriented towards the patient without due consideration of the needs of the informal caregivers whose lives were greatly impacted at all levels (professional, social and family life) as a result of their caring activity. This inattention to the needs of caregivers is due to an unrealistic fear that support would lead to an exponential increase in health costs.

5.2.1. Best practices

37. There are many ways to support informal caregivers and there are many examples of such support in Council of Europe member states. In Luxembourg, for example, relatives who provide care are protected against the financial losses resulting from a reduction of their working hours via a special insurance scheme. In Sweden, France and Austria, there is statutory unpaid leave for care-providing relatives and, in Sweden, financial support is available for caregivers. In Ireland, allowances are paid, at various levels and subject to means, to qualifying carers.

38. Measures to offer informal caregivers respite are also important. In Lyon (France), a pilot project called "Caring Metropolis" aimed at offering various services to home-based patients and their carers is currently being conducted. The project, supported by national and regional authorities, includes a "respite house" where patients and families can stay temporarily (30 days a year) and receive medical and other services such as psychosocial support and the possibility of spending time on leisure and well-being activities (for informal caregivers). A mobile team within the respite house - comprising doctors, nurses, psychologists and social workers - assist families before, during and after their stay, including by providing bereavement support. The project also includes information, orientation, and individualised support, training and workshops for carers.

39. Other measures which may be implemented at member state level to assist families and carers include: encouraging a shared approach between healthcare professionals and family members in

⁴³ Notwithstanding the positive dimension of opioid-based pain management, the recent crisis in the US has highlighted the need for appropriate education for healthcare staff and members of the public about the use of opioids in pain management – for example, see www.cdc.gov/drugoverdose/prescribing/guideline.html.

⁴⁴ See footnote 38, page 275.

⁴⁵ Fact sheet on "Why addressing the needs of informal carers is a crucial issue for Europe?," European Association working for carers.

relation to the care of the patient; offering clear choices to family members to become involved in the care of their loved one at a level which they feel is appropriate for them; clear lines of decision-making and a flow of information to carers from healthcare professionals about the treatment of the patient; clear and frank information about the patient's prognosis (subject to his or her wishes), particularly towards the end of life, to allow the carer to prepare themselves and to cope with this information; anticipation of the impact which the death of the patient may have on caregivers and family members; and the provision of bereavement support after the death of the patient.

5.2.2. Gender dimension of informal care

40. Across the EU, a majority of the 100 million informal carers are women, typically spouses, middle-aged daughters or daughters-in-law, aged 45 to 75. This disparity between men's and women's participation in caregiving explains some structural features of female employment, such as its concentration in some sectors, the gender employment and wage gap and higher temporality and extent of part-time jobs among women. This issue should be addressed, not just in terms of financial support for those who engage in caregiving, but also in the structuring of workplace arrangements so as to facilitate the task for women and men who want to take up the role of informal caregiving in their particular situation. With the increase in the need for caregiving, the pressures of juggling work and caregiving roles will increase and the current system will become unsustainable.⁴⁶

41. Decisions on informal caregiving are for individuals and families to make for themselves, having regard to their particular personal or family situation, aptitudes, capacities etc. Labour legislation and regulations which provide for family-related leave and flexible working arrangements - which women tend to disproportionately make use of for obvious reasons - should be accompanied by cultural, financial and employment measures aimed at removing any other barriers to women and men engaging in informal caregiving (for example, by facilitating paid leave for both men and women in such instances).⁴⁷

5.3. Lack of training

42. According to WHO, lack of training and awareness of palliative care among health professionals is an important barrier to improving access to this type of care. As indicated above, prejudice and misinformation about the appropriate medical use of opioids is a major problem, including amongst health-care professionals. Many doctors also can't bring themselves to mention the term 'palliative care' because of possible negative connotations (see below), leading them to postpone any offer to provide such care, instead continuing for far too long to prescribe medical treatments that have become ineffective.⁴⁸ Moreover, physicians feel like they are failing or letting patients down and abandoning them by raising the subject of palliative care services.⁴⁹ Many still do not understand that palliative care can be provided concurrently with curative treatments.

43. Consequently, training of health professionals should include the acquisition of competences in pain management and controlling other symptoms. They should also learn how to approach and take into account social, emotional and spiritual needs, how to support families before and after the patient dies, and how to work in a team. Palliative care nurses should acquire skills in the early recognition of

⁴⁶ The factsheet on "The gender dimension of informal care", European Association working for carers.

⁴⁷ The Irish Constitution contains a clause dating back to 1937 which recognises the contribution of women to life within the home and the Irish Government has recently announced a referendum to remove this provision. The Government's plan faces opposition from different quarters. Some argue that the clause should not be removed but instead replaced by a gender-neutral provision which would recognise the role of parents and perhaps carers in general in the home setting.

⁴⁸ See footnote 19.

⁴⁹ See footnote 11.

signs and symptoms, possess excellent communication skills and above all, should be able to deal with the ongoing reality of caring for dying patients and their distressed families.⁵⁰

44. It has been claimed that early recognition of palliative medicine as a medical speciality in the United Kingdom has been a hallmark of the development of palliative care in the country. Today, there is no European-wide recognition of palliative medicine as a medical speciality, with it having speciality status in two European countries only, Ireland and the United Kingdom. Mandatory undergraduate education in palliative care, as part of a harmonised public health approach for Europe, would be one of the most effective measures in the improvement of end-of-life care.⁵¹

45. Poor public awareness and public misconceptions also constitute barriers to accessing palliative care. Because at the outset palliative care was developed for patients at their end-of-life stage, for many Europeans the prescription of palliative care is therefore perceived as an announcement that death is imminent. Many don't know what services are available under the heading of palliative care or don't understand the term at all. This is also one of the main conclusions resulting from the survey which I sent out to my contacts (see paragraph below).

5.4. Psychological, spiritual and emotional support

46. Optimal palliative care includes not only appropriate medical and therapeutic interventions but also psychological, spiritual and emotional support. As part of the palliative care team, the psychologist, social worker, faith leader, minister or counsellor all play critical roles that extend beyond the management of the psychological symptoms and syndromes of patients into areas that include existential issues, family and caregiver support, and bereavement. The Vatican Pontifical Academy for Life has recently stressed the need for such spiritual care to be provided at local and state level⁵² and indeed this concern for the provision of spiritual care is shared across different faiths and denominations.⁵³ However, the provision of such support often remains scarce. In fact, as Rapporteur, I sent out a survey to my contacts, inviting them to share their experiences of palliative care. Many participants who are based in Ireland and the United Kingdom regretted a lack of psychological and spiritual support, as well as the fact that families often have to take the initiative to ask for spiritual or psychological support rather than these being offered automatically. This is notwithstanding the fact that palliative care provision operates to a high standard in each of these countries.⁵⁴

47. In Spain, this kind of support is offered to patients through different mechanisms, including a public-private collaboration whereby La Caixa Foundation together with the Ministry of Health is financing and implementing the "Programme for the Comprehensive Care of Patients with Advanced Chronic Conditions and their Families". This programme aims at addressing the emotional, social and spiritual needs of patients with advanced diseases and their families and complements already existing palliative care services. It does this by providing teams of professionals to carry out psychosocial and spiritual interventions for people who are at the end of life as well as for their families. The programme provides psychosocial care teams in 17 autonomous communities in Spain, which operate both in hospitals and at patient's homes. It provides teams with the necessary training, support and monitoring to enable them to perform their duties. Multidisciplinary teams are composed of psychologists, doctors, nurses, social workers, pastoral workers and volunteers. In Spain, there are

⁵⁰ "Assessing Organisations to improve palliative care in Europe", edited by Sam H Ahmedzai, Xavier Goméz-Batiste et al., 2010.

⁵¹ Ibidem.

⁵² White Paper for Global Palliative Care Advocacy of the expert advisory group of the Pontifical Academy for Life (March 2018).

⁵³ For example, see the Buddhist Spiritual Care Centre at Dzogchen Beara, Co Cork, Ireland – www.dzogchenbeara.org

⁵⁴ "The Quality of Death Index 2015", published by The Economist Intelligence Unit and commissioned by the Lein Foundation, ranked the United Kingdom and Ireland first and fourth respectively in the provision of palliative care.

also a number of NGOs (for example the Spanish Association against Cancer) providing psychosocial support for patients and families and helping them with the management of everyday activities.

6. Palliative Care for Children

48. Although the WHO definition of palliative care for children⁵⁵ is similar to that for adults, there are some very distinct differences between adult and children's palliative care. In particular, most children requiring palliative care have non-cancer conditions and are born with life-limiting or life-threatening conditions which are often coupled with chronic and complex disabilities. Many of these life-limiting conditions in children are extremely rare and specific to childhood, and the timescales involved in the provision of palliative care can be much longer than for adults.

49. There are major disparities in the development of children's palliative care services within and between the 47 Council member states. Several countries, including Ireland, Italy, and the United Kingdom have undertaken national needs assessments aimed at identifying the requirements of children with life-limiting conditions and their families⁵⁶. Most children requiring palliative care will have their care needs met by their family at home supported by locally-provided services. Parents often take on the role of primary carer, often impacting on their ability to care for their other children and to contribute to the financial and practical running of their household. More so than in adult palliative care, respite care has been identified as an essential part of enabling parents to care for their sick child at home.⁵⁷

50. As a speciality, palliative care for children has evolved from paediatrics rather than through palliative care. This is in line with the provisions of the United Nation Convention on the Rights of the Child to the effect that children are best cared for by those specifically trained and experienced in the care of children⁵⁸. Unfortunately, such a paediatrics-driven evolution of children's palliative care is not reflected in certain countries where there is a lack of resources and services.

51. To develop palliative care for children, education and training of healthcare professionals is essential at all levels. A core curriculum for healthcare professionals has been developed by the European Association of Palliative Care⁵⁹ but courses specifically relating to palliative care for children are not widely available. It is also vital that the voice of the child is heard in the delivery of health care and palliative care. Children's palliative care has been recognised as a medical speciality in its own right in the United Kingdom and this is something that should be considered by other member states.

7. Conclusions

52. Palliative care provision is about more than services. It is about respect for human dignity and human rights. The traditional focus of healthcare systems on prevention, diagnosis and cure must shift towards a more comprehensive system, to include adequate palliative care services which improve the quality of life of patients with life-threatening and life-limiting conditions, allowing them to live well until they die.

⁵⁵ WHO <http://www.who.int/cancer/palliative/definition/en/>

⁵⁶ IMPACCT Standards of Pediatric Palliative Care - <http://www.eapcnet.eu/LinkClick.aspx?fileticket=ShMQyZuTfqU%3D>

⁵⁷ Ling (2015) <http://cpccconf.ie/media/Dr-Julie-Ling-Home-is-Where-the-Heart-is-providing-respite-in-Childrens-Palliative-Care.pdf>

⁵⁸ United Nations Convention on the Rights of the Child (1989).

⁵⁹ <http://www.eapcnet.eu/LinkClick.aspx?fileticket=6elzOURzUAY%3D>

53. Countries cannot meet Goal 3, Target 3.8 of the Sustainable Development Goals: “Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all” without including palliative care and pain relief. With a view to providing optimal standards of palliative care, member states should adopt laws that acknowledge and define palliative care as part of national and regional healthcare systems, incorporate it directly into national health strategies/programmes, and make it accessible to all patients who need it. Palliative care services still focus on terminal cancer and must urgently be extended to all patients with any kind of chronic condition who could benefit thereof. Adapting palliative care services to serve non-cancer patients with advanced chronic conditions is a challenging but critical exercise for healthcare systems and will involve considerable amounts of investment both in terms of infrastructure and personnel, but has the potential to bring down costs over time, while meeting the needs of the patients concerned and their families and caregivers.

54. Member states should overcome legal, regulatory, educational, and attitudinal obstacles that restrict availability and access to pain-relieving medications in a palliative care setting, and provide adequate support for informal caregivers. Considering that comprehensive palliative care provision requires the involvement of multidisciplinary teams of professionals, the provision of education/training (from basic to postgraduate levels) should be prioritised. Member states should review education curricula to ensure that healthcare workers such as doctors and nurses receive sufficient training in palliative care and pain management. They should also consider collaboration with the voluntary and private sectors in the provision of palliative care services. Finally, member states should always have regard to the essential role of research in the development and improvement of palliative care services.