

Constructing a Right to Palliative Care: The Inter-American Convention on the Rights of Older Persons

Construyendo un derecho a los cuidados paliativos: la Convención Interamericana de derechos de las personas mayores

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‘To promote the provision of ‘Palliative Care as a human right’ is admirable advocacy’.

Abstract: Since its conception nearly ten years ago, efforts to reach a universally acceptable definition of a ‘right to palliate care’ have been largely unsuccessful, mainly since the debate so far has been substantially on an abstract philosophical/legal level rather than arising out of the real experience of terminally ill people struggling to achieve rights and addressing their immediate needs. As an alternative to the problem of achieving a philosophical/legal definition of a right to palliative care, this work elaborates a strategy of constructing a right to palliative care through the interpretation of how a right to administer palliative medicines is embodied in current soft and hard law instruments. To illustrate how this may be done, the Inter-American Convention on the Rights of Older Persons (ICROP) is used as a case study. An analysis of the ICROP reveals the extent to which it embodies values associated with a right to palliative care: fundamental rights and freedoms that recognize human dignity; encompassing traditional health rights; the right to live a dignified existence; positive rights. The increasing experience people gain with the complex issues arising out of a right to health care conceived as affordable and comprehensive for everyone could generate further texts explicitly referring to a right to administer palliative medicines. Analysis of such texts may reveal that, in time, everyone does indeed have a right to care, including palliative care.

Resumen: Desde que apareciera a nivel conceptual hace diez años el “derecho a los cuidados paliativos de pacientes en fase terminal”, los esfuerzos para alcanzar una definición aceptable del mismo a escala universal han sido infructuosos debido a que el debate se ha centrado en un plano filosófico y normativo abstracto y no tanto en la experiencia real de las personas en situación terminal que aspiran a ver satisfechas sus necesidades y a que su derecho sea efectivo. Como alternativa al problema de

lograr una definición ius filosófica del derecho a los cuidados paliativos, este estudio defiende la adopción de una estrategia consistente en la construcción de este derecho a partir de la interpretación de actuales instrumentos internacionales tanto vinculantes (hard law) como no vinculantes (soft law) que reconocen un derecho a recibir medicinas paliativas. A modo de ilustración, la Convención Interamericana de los derechos de las personas mayores sirve como estudio de caso en la medida en que incorpora valores asociados a un derecho a los cuidados paliativos: derechos y libertades fundamentales que reconocen el principio de la dignidad humana; incluye tradicionales derechos a la salud; contempla el derecho a vivir con dignidad junto a derechos positivos. La progresiva experiencia de personas a partir del reconocimiento de un derecho a los cuidados médicos concebido como un derecho real, al alcance de todos, podría generar nuevos instrumentos normativos que de modo explícito contemplaran un derecho a la administración de medicina paliativas. El análisis de tales textos puede revelar que con el tiempo todos sean titulares de un derecho a los cuidados médicos, incluyendo los cuidados paliativos de pacientes en fase terminal.

Keywords: Right to Palliative Care; Older People’s Rights; The Inter-American Convention on the Rights of Older Persons.

Palabras clave: Derecho a cuidados paliativos; derechos de los mayores; La Convención Interamericana de los derechos de los mayores.

1. Introduction.

The management of patients, particularly of those with cancer, is clearly an exceedingly complex issue, but every patient has, among others, two fundamental needs: to achieve well-being throughout their existence, and to be free of suffering and pain.¹ I contend, as have others, that these two needs are the foundation for a right to palliative medicines that every person affected by serious sickness requires for improving the quality of his or her existence. To be unable to escape suffering and pain is an indignity to the individual. In this regard, it is worth recalling that ‘the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment’ according to the UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or

¹ See *ex multis* Lohman D, Schleifer R, Amon JJ., ‘Access to pain treatment as a human right’, (2010) *BMC Med.*, available at: <http://www.ncbi.nlm.nih.gov/pubmed/20089155> (last accessed 13 October 2015).

Punishment.² Moreover, it is also worth recalling that dignity is a unifying concept for human rights and palliative care.³

Since freedom from pain and suffering is so fundamental to being a fully dignified human being, every patient has a right to palliative care rooted in law. Nevertheless, ever since Frank Brennan acknowledged the necessity for a right to palliative care as a fundamental right in 2007, achieving the entrenchment of this right in national or international law has been hampered by the challenge of shaping it.⁴ Health rights activists, policy experts, academics, and others have advanced a multiplicity of interpretations but no precise definition has attained widespread acceptance.⁵ Much of this discussion on definition is at an abstract philosophical and legal level of discourse. Although such a discussion is valuable in exploring what might represent a right to palliative medicines, it has been, until recently, detached from the experience of the large majority of patients. Therefore, it has not been associated with a broad-based political or social experience that might bond theory and practice. Instead of trying to describe a right to palliative care, this paper explores a strategy of constructing a right to palliative care using as a case study the Inter-American Convention on the Rights of Older Persons (ICROP), adopted by the General Assembly of the Organization of American States (OAS) on June 2015.⁶

2. From Describing to Building A Human Right to Palliative Care.

Another strategy in addition to the established one of trying to devise a philosophical/legal definition of a right to palliative care (in order not to confuse it with euthanasia) is to interpret how the values usually associated with a right to palliative care are expressed in current declarations, agreements, policies, and judicial rulings of international and domestic legal institutions. Philosophical and

² Nowak M and Hunt P. Special Rapporteurs on the question of Torture and the Right of everyone to the highest attainable standard of physical and mental health. Letter to Mr D. Best, ViceChairperson of the Commission on Narcotic Drugs, December 10 2008.

³ See Frank Brennan, ‘Palliative care as an international human right’, (2007) 33 (5) *J Pain Symptom Manage*, pp. 494-499.

⁴ See below paras 8 and 9.

⁵ An exception might be the WHO Definition of Palliative Care, according to which: ‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, physical, psychosocial and spiritual’.

⁶ The text of the Inter-American Convention on the Rights of Older Persons, in English, is also available at OAS’ official website: www.oas.org.

legal discussions, although essential, tend frequently to conclude with definitions so general that they are disconnected from patients’ real experience. Here, it is important to acknowledge the successes in attaining rights arising from severely ill patients’ often long struggles to have a remaining life free of pain and major suffering. As the UN Committee on Economic, Social and Cultural Rights (CESCR) points out, it is critical to provide: ‘attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity’.⁷ Furthermore, to quote Professor Ronald Dworkin, it is important to realize that if human beings are to ‘retain the self-consciousness and self-respect that is the greatest achievement of our species, [we] will let neither science nor nature simply take its course, but will struggle to express, in the laws [we] make as citizens and the choices [we] make as people, the best understanding [we] can reach of why human life is sacred, and of the proper place of freedom in its dominion.’⁸

Since a reasonable understanding of the right to health may be that every person is allowed to support what would guarantee his or her optimum health taking into account his actual physical and/or biological conditions,⁹ it must be possible to establish, through analysis of several texts that incorporate this right, whether the values of a right to palliative care are being accomplished regardless of the absence of a specific and universally accepted definition. Indeed, this paper contends that the features of a human right to palliative medicine are encompassed in the foundational International Covenant on Economic, Social and Cultural Rights (ICESCR), specifically Articles (12) on the right to the highest attainable standard of physical and mental health, (19) the right to food, and (11) non-discrimination and right of self-determination (1).¹⁰ Significantly, the European Association of Palliative Care, which, in collaboration with other bodies, proclaimed *The Prague Charter for Palliative Care as a Human Right*, argues that ‘health’ is to be defined broadly and must include the health of people with life-limiting illnesses.¹¹ In particular, the

⁷ CESCR General Comment N. 14, paragraphs 34 and 25, respectively.

⁸ See R. Dworkin, *Life’s domination: An argument about abortion and euthanasia*, New York: Knopf, 1993. pp. 240-41.

⁹ See e.g. Brigit C.A. Toebes, *The right to health as a human right in international law*, Antwerpen: Intersentia, 1999, Ch. V.

¹⁰ UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: <http://www.refworld.org/docid/3ae6b36c0.html> [accessed 14 October 2015]

¹¹ The text of the Charter, in English, is also available at: https://secure.avaaz.org/en/petition/The_Prague_Charter_Relieving_suffering (last accessed 14 October 2015). On the subject, see Esther Schmidlin and David Oliver, ‘Palliative care as a human right: what has the Prague Charter achieved?’, (2014) 22 (3) *Eur J Pall Med*, pp.141 - 143; Radbruch L, De Lima L, Lohmann D, Gwyther E, Payne S., ‘The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care’, (2013) 27 (12) *Palliative Medicine*, pp.101-102

European Association of Palliative Care reveals how the values of the right to palliative care are entrenched in the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Convention on the Rights of the Child (CRC), as regards some of the most discriminated and vulnerable subjects.¹² This is confirmed by the fact that the Preambles to each of these UN Conventions respectively restate the principle of the dignity and worth inherent to all human persons. Furthermore, Liz Gwyther has examined issues related to terminally ill patients in the framework of a right to palliative care.¹³ Through such a purposive perspective approach, a consistent body of interpretation and analysis may be accumulated, which creates an accepted formulation of a right to palliative medicine.

To validate this interpretative approach, this paper considers how values associated with a right to palliative care are entrenched in the recently enacted Inter-American Convention on the Rights of Older Persons (ICROP), a treaty resulting from years of struggle by elderly persons to achieve recognition of rights associated with their unique and vulnerable status. It includes a range of rights not normally explicitly incorporated in treaties, such as access to ‘palliative care’, or the notion of ‘active and healthy ageing’. The specific Articles upon which we draw in analyzing the right to the values of palliative care embodied in the ICROP are Articles (2); (11); (12) and (19).

3. The Inter-American Convention on the Rights of Older Persons (ICROP).

The population of the ‘elderly’ in America and in almost all parts of the planet is rising fast -faster than the overall general population. At present, people aged 60 or older in the Americas represent 14 percent of the hemisphere's population (over 135 million). By 2030, nearly two in five people will be 60 or older, and in total there will be more than 215 million older people in the Americas.¹⁴ According to the

¹² References are found in FXB Center for Health & Human Rights, ‘Health and Human Rights Resource Guide’, available at: http://hhrguide.org/wp-content/uploads/sites/25/2014/03/HHRRG_Chapter-5.pdf (last accessed 12 October 2015).

¹³ See Liz Gwyther, ‘Palliative Care as a Human right’, available at: <http://www.cancercontrol.info/wp-content/uploads/2014/08/116-121-Gwyther.pdf> (last accessed 12 October 2015).

¹⁴ OAS, The Americas Becomes First Region in the World to Have an Instrument for the Promotion and Protection of the Rights of Older Persons, available at: https://www.oas.org/en/media_center/press_release.asp?sCodigo=E-198/15 (last accessed 15 October 2015).

Organization of American States (OAS), older persons are often pushed to the peripheries of society and **deprived of fundamental** human rights.¹⁵ Therefore, their fight for fundamental rights has been lengthy and hard. The ICROP in fact is the culmination of over two decades of negotiations. The OAS began its official involvement with the issue of older persons with the creation of a Working Group on the Protection of the Human Rights of Older Persons in 2007, which developed the initial draft of the ICROP. In 2009, the OAS General Assembly launched the Plan of Action on the Health of Older Persons, and, in 2012, the General Assembly enacted a preliminary draft of the Inter-American Convention on Protecting the Human Rights of Older Persons. After much negotiation, the Convention was adopted by the General Assembly on 15 June 2015.

It is important to stress here that the ICROP is a legally binding text - unlike, for instance, the OAS Declaration of the Rights of Indigenous Peoples (OAS-DRIP).¹⁶ In the same way as the OAS-DRIP, the ICROP has served since its enactment as a moral source for people throughout the American hemisphere to draw upon in their struggle for fundamental rights and liberties, the substantive vote in favour of the ICROP also carries considerable moral force.¹⁷ It is clear from the drafting history of the ICROP, the first regional tool of its kind on the planet, that this text does not embody the views of all members of the OAS.¹⁸ Nevertheless, it sets international guidelines and standards, and a structure from which states can enhance the human rights of their older persons, including and in particular, the right to health, the right to life and dignity in old age, the right to express their free and informed consent on health matters, the right to a healthy environment, and the right to be integrated into the community. On the other hand, the new Inter American Convention calls on countries to offer comprehensive care to the elderly, including palliative medicine, and to prevent unnecessary suffering and useless procedures. It also requires countries to encourage and increase research and academic training for palliative care, as well as specialized health professionals in geriatrics and gerontology. Furthermore, the ICROP demands that both private and public healthcare, and long-term care organizations, offer access to palliative care, and that governments

¹⁵ Ibidem.

¹⁶ UN General Assembly, United Nations Declaration on the Rights of Indigenous Peoples : resolution / adopted by the General Assembly, 2 October 2007, A/RES/61/295, available at: <http://www.refworld.org/docid/471355a82.html> [accessed 14 October 2015].

¹⁷ The Inter-American Convention on the Human Rights of Older Persons was immediately signed by Argentina, Brazil, Chile, Costa Rica, and Uruguay,

¹⁸ To date, five countries in the Americas —Argentina, Brazil, Chile, Costa Rica and Uruguay—have signed the Convention. On this issue, see HUMAN RIGHTS WATCH, ‘A Victory for Palliative Care Access in the Americas’, available at: <https://www.hrw.org/news/2015/07/20/victory-palliative-care-access-americas> (last accessed 15 October 2015).

guarantee access to essential pain medications for older persons.¹⁹ For that, it must be perceived as one major achievement in the advancement of human rights of vulnerable subjects and groups. It remains to be seen, however, if the ICROP can also function as a model for a future UN Convention for the Rights of Older Persons.²⁰

4. A Human Right to Palliative Care for Older Persons?

Since the early 2000s, attempts to describe a right to palliative medicines have been made by various subjects, including, among others, the World Health Organization (WHO), non-governmental organizations (NGOs), and academics and human rights activists. While debate over the meaning and contents of a human right to palliative care continues, a number of values are consistently associated with such a right. One of the first attempts to enunciate such a right was made in 2002 by the WHO, which stated: 'Palliative Care as an approach that improves the quality of life of patients and their families facing the 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, physical, psychological and spiritual'.²¹ This definition was successively developed in WHO recommendations.²² These include the provision that all countries must approve a national palliative care policy, guarantee the training and education of health professionals and foster public awareness, and guarantee the availability of morphine in all health care settings. and that all countries must guarantee that minimum standards for pain relief and palliative care are gradually adopted at all levels of care.

¹⁹ *Amplius* F. Seatzu, ‘Sulla convenzione dell’organizzazione degli stati americani sui diritti delle persone anziane’, (2015) 31 *Anuario español de derecho internacional*, p. 349 ff.

²⁰ On the debates focusing on a UN Convention of the rights of older persons, see among others J Williams, ‘An International Convention on the Rights of Older People?’, in M Odello and S Cavandoli (eds), *Emerging Areas of Human Rights in the 21st Century—The Role of the Universal Declaration of Human Rights* (Abingdon, Routledge, 2011) 129 ff; C. Martin, D. Rodríguez-Pinzón, ‘The international human rights status of elderly persons’, (2003) 16 *American University International Law Review*, p. 915 ff. See also F Mégret, ‘The human rights of older persons: a growing challenge’ (2011) 11 *Human Rights Law Review*, pp. 37-66.

²¹ World Health Organization 2011, WHO definition of palliative care, available at: www.who.int/cancer/palliative/definition/en/ (last accessed 15 November 2015).

²² Incidentally, it is worth observing that in response to a request by WHO, the International Association for Hospice and Palliative Care convened a group of palliative care experts, in 2006, to develop a list of Essential Medicines for Palliative Care.

In more general terms, the WHO recommendations provide a further guide to the minimum standards expected by the international community.²³

In the same years, The Cape Town Declaration, adopted at a conference of African palliative care trainers held in South Africa in 2002, describes a right to palliative care as: '.... a right of every adult and child with a life-limiting disease'.²⁴ Even more interestingly, the Cape Town Declaration further stresses that: 'Appropriate drugs, including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and at all levels of care, from hospitals to community clinics and homes'.²⁵ Again, it provides that: 'Palliative care should be provided at all levels of care: primary, secondary and tertiary'. *Mutatis mutandis*, there is a similar approach in the Recommendation Rec (2003) 24 of the Committee of Ministers of the Council of Europe, which identifies 'palliative care as... an inalienable element of a citizen's right to health care'.²⁶

More recently, the International Working Group (European School of Oncology) offered the following description: 'the person-centered attention to physical symptoms and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimize the quality of life of patients and their families or friends'.²⁷ Of special relevance here are two further refinements which reflect the levels at which palliative care can be delivered, namely: 'Basic palliative care is the level of palliative care which should be provided by all health professionals, in primary or secondary care, within their duties to patients with life-limiting disease'; and 'Specialized palliative care is the standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialized educational and practical resources to other non-specialist members of the primary or secondary care teams'.²⁸

²³ See C Sepúlveda, A Marlin, T Yoshida, A Ullrich, 'Palliative care: the World Health Organization's global perspective', (2002) *Journal of Pain and Symptom*, pp. 91-96.

²⁴ See Mpanga Sebuyira L, Mwangi-Powell F, Pereira J, Spence C., 'The Cape Town Palliative Care Declaration: home-grown solutions for sub-Saharan Africa', (2003) 6 (3) *J Palliat Med.*, pp. 341-3.

²⁵ Ibid.

²⁶ Council of Europe, *Recommendation Rec (2003) 24 of the Committee of Ministers to Member States on the organisation of palliative care and Explanatory Memorandum*, available at: [http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec\(2003\)24.asp](http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec(2003)24.asp). 2003.

²⁷ For further references see Sam Hjelmeland Ahmedzai, 'A new international framework for palliative care', (2004) 40 (15) *European Journal of Cancer*, pp. 192-200.

²⁸ Ibid.

Last but not least, it is worth mentioning the contribution by the *Montreal Statement on the Human Right to Essential Medicines* (2005).²⁹ The Statement expressly links the international right to health to universal access to these essential medications.

For the purpose of this paper, each of these values will be examined with specific reference to the ICROP.

5. A Regional Human Right Acknowledging the Right to Palliative Care.

It was not until the adoption of the ICROP in 2015 that the concept of the right to palliative care was accepted at the international level in a formally approved text. As this new fundamental right is advanced, debate continues over the relationship between this right and other core civil and socioeconomic rights and freedoms such as the right to adequate health, life and food.

The ICROP affirms the concept of the right to palliative care within the framework of the protection of older persons.³⁰ Article (2) defines ‘palliative care’ as ‘the active, comprehensive, and interdisciplinary care and treatment of patients whose illness is not responding to curative treatment or who are suffering avoidable pain, in order to improve their quality of life until the last day of their lives’. Moreover, the same Article proclaims that: ‘Central to palliative care is control of pain, of other symptoms, and of the social, psychological, and spiritual problems of the older person. It includes the patient, their environment, and their family. It affirms life and considers death a normal process, neither hastening nor delaying it’. The ICROP, in other Articles, also recognizes a duty of the Contracting States to encourage and strengthen academic training for palliative care and research, as well as specialized health professionals in geriatrics and gerontology. Moreover, the ICROP requires that both public and private healthcare, and long-term care institutions, provide access to palliative care, and that governments ensure access to

²⁹ See T. Pogge, ‘Montréal Statement on the Human Right to Essential Medicines’, (2007) 16 *Cambridge Quarterly of Healthcare Ethics*, pp. 97-108.

³⁰ See also Marlies Hesselman, ‘Inter-American Human Rights Treaty on the Rights of Older People Defines a Broad Scale of (New) Health Rights: Precedent for a UN Treaty?’, available at: <https://ghlgblog.wordpress.com/2015/09/08/inter-american-human-rights-treaty-on-the-rights-of-older-people-defines-a-broad-scala-of-new-health-rights-precedent-for-a-un-treaty/> (last accessed 12 October 2015) (stressing that older persons experience increased rates of chronic and terminal illnesses, and therefore represent a significant portion of the population that requires palliative care, and that there are about 605 million people aged 60 years and over, and WHO expects that number to increase to 2 billion by 2050, with low- and middle-income countries experiencing the most rapid changes.)

essential pain medications for older persons. Nevertheless, despite these reform-minded efforts, it does not address vital legal features of palliative care, such as concerns related to inheritance laws and the future of the patient’s property, access to social benefits, patient confidentiality, and the care of children and grandchildren. This is despite the fact that these legal concerns are firmly linked to emotional distress during end-of-life care, and tackling them is part of palliative care’s holistic approach.

Therefore, seen in this manner, older persons have the right to initiate the transition from curative to palliative care, which allows pain and distressing symptoms of disease to be effectively alleviated in all but the most extreme situations (Article (2)), and to maintain and strengthen their health condition (Article (19)). The right to palliative care is further elaborated upon with regard to rights to life and dignity in old age (Article (6)); to receive long-term care (Article (12)); to protection from any kind of violence or mistreatment, (Article (9)); and to protection from torture or cruel, inhuman, or degrading treatment or punishment (Article (10)).

As if to drive home its acknowledgement of a right to palliative care, Article (7) states: ‘older persons have the right to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights’. Furthermore, to protect their right to choose between hospice care and curative care, they have the right, according to Article (11), to give free and informed consent on health matters. It is clear that the ICROP does not see a conflict between recognized universal rights and rights arising out from the use of palliative care.

6. The Relationship between the Right to Palliative Care and the Right to Health Care.

The ICROP addresses a number of well-being issues that have been embedded in traditional fundamental freedoms and rights, such as freedom from torture, the right to life, the right to health and to health care, and the right to personal mobility. However, because of the features of health care systems for older persons, which differ substantially from the health care systems for the rest of the population³¹, the ICROP challenges current interpretations of such rights and therefore can be potentially seen (and used) as a threat to traditional approaches to health care.

Advocates of a right to palliative care never envisaged it would be an alternative for well-established health care rights. Rather, they believe these rights are

³¹ See *Amplius* S.L. Reynolds, ‘A Tale of Two Countries—the United States and Japan: Are Differences in Health Due to Differences in Overweight?’ (2008) 18 (6) *J Epidemiol.*, pp. 280-290.

strengthened by being placed within a broader framework of an ascending progression of freedoms and rights whose capstone is a right to lead a decent and dignified life. In contrast with assertions of traditional health care freedoms, this framework places them in a context of individual and age diversity. By addressing such issues the ICROP reinforces the values logically associated with a right to health care and to a dignified life.

The issue of medical freedom is addressed in Article (11) which states that ‘Older persons have the right freely to consent to, refuse, or suspend medical or surgical treatment—including that of the traditional, alternative, and complementary kind—research, or medical or scientific experiments, whether physical or psychological, and to be given clear and timely information about the potential consequences and risks of such a decision.’ Equally important, Article (11) also provides that: ‘States Parties shall also establish a procedure that enables older persons to expressly indicate in advance their will and instructions with regard to health care interventions, including palliative care. In such cases, that advance will may be expressed, amended, or expanded at any time by the older person only through legally binding instruments in accordance with domestic law’. Article 12 gives older persons the right to a comprehensive system of care that protects and promotes their health, provides social services coverage, food and nutrition security, water, clothing, and housing, and promotes the ability of older persons to stay in their own home and maintain their independence and autonomy, should they so decide. It also calls upon states ‘to adopt measures toward developing a comprehensive care system that takes particular account of a gender perspective and respect for the dignity, physical, and mental integrity of older persons’.

Traditional health rights place great emphasis on curative care. Nevertheless, as indicated above, a right to health care also encompasses the right of individuals to non-curative (or palliative) care. For older persons suffering from terminal illness, the manner of preventing suffering is of primary significance; consequently, access to health care services cannot be reduced to curative and rehabilitative commodities.³² Article (2) protects this approach including ‘the right to a differentiated treatment for the effective enjoyment of rights of older persons’.

The protection of the health care rights of older persons is a high profile issue. Free and informed consent on health matters is addressed in Article (11), which makes reference to the right of older persons to express their consent in a voluntary, free, and explicit manner to any medical decision, treatment, procedure, or research in the area of health. Older persons are granted the specific ‘right to modify or revoke such consent’.

³² Accordingly, the United Nations Committee on Economic, Social and Cultural Rights (CESCR) states that, with regard to the realization of the right to health of older persons, ‘attention and care for chronically and terminally ill persons [is important], sparing them avoidable pain and enabling them to die with dignity.’

The right to physical and mental health without discrimination of any kind is manifest throughout the ICROP in several ways, some of which have already been touched upon. These include references to the right to primary care-based social and health care services, and take advantage of conventional, alternative, and complementary medicine, in accordance with customs and domestic laws. Indeed, the essence and objective of the ICROP as a whole is the protection of the proactivity, independence and autonomy, in all its manifestations, of older persons.

7. Enhancing the Right to a Dignified Life for Older Persons.

The promotion of a right to palliative care in the 2000s was part of a broader debate on human dignity. Early advocates of a right to palliative care acknowledged that palliative care is a public health priority, not only because of the societal impact on caregivers and survivors and the significant financial issues that impact families and communities with chronic disease, but also because of its impact on the enjoyment of the right to a dignified life (‘vida digna’). They embraced the idea that palliative care has a remarkable potential to avoid both present distress and potential illness: present suffering with the illness itself; and future disease through its objective of care for the family, during which people at risk of disease can be advised to take screening tests.

Their foresight was asserted when significant advances occurred in the prevention, diagnosis and treatment of illnesses. These advances renewed a call for the institution of hospices for the treatment of patients with chronic illnesses in numerous countries, and produced awareness that, contrary to older statements, the advancement and defence of fundamental rights (including the right to human dignity) and health are ‘inextricably linked’.³³ The ICROP makes explicit reference to the right of life and the right to live with dignity in old age until the end of life and on an equal footing with other people. Article (6) states:

1. States Parties shall adopt all measures necessary to ensure older persons’ effective enjoyment of the right of life and the right to live with dignity in old age until the end of their life and on an equal basis with other segments of the population.

2. States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care; avoid isolation; appropriately manage problems related to the fear of death of the terminally ill and pain; and prevent unnecessary suffering, and futile and

³³ See e.g. JM. Mann, ‘Health and Human rights’. in Mann JM, Gostin L, Gruskin S et al, eds. *Health and Human Rights: A Reader*, 1st ed., New York: Routledge; 1999:35-53.

useless procedures, in accordance with the right of older persons to express their informed consent.

Mutatis mutandis, the same line of reasoning can be found in Article (9), para. 1, which provides that:

Older persons have the right to safety and a life without violence of any kind, to be treated with dignity, and to be respected and appreciated regardless of their race, color, sex, language, culture, religion, political or other opinions, social origin, nationality, ethnicity, indigenous and cultural identity, socio-economic status, disability, sexual orientation, gender, gender identity, economic contribution, or any other condition.

8. Positive Rights at the Domestic and International Level.

From the beginning, advocates of a right to palliative care considered it as a positive right, which is to say that the state has the duty to guarantee that nationals have the resources indispensable to exercise their right. A good example of this approach may be found in Professor Margaret Somerville’s writings, according to which the unreasonable failure to deliver pain relief treatment constituted negligence.³⁴ Two facts bring the author to this reach conclusion: a) the existence of a ‘common thread linking respect for persons’ with ‘respect for their human rights, medicine, ethics and law’; b) leaving ‘patients in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights’.³⁵ Nonetheless, a right to palliative care requires not only national but international action, primarily because of the free movement of patients across borders - or patient mobility, as it is usually referred to.

Action at both the national and international level is called for in the ICROP. Article after article stipulates, with regard to a wide range of rights, ‘States shall provide effective judicial protection’; ‘States Parties shall promote the adoption of expedited procedures for complaints and redress in the event of evictions of older persons and shall adopt the necessary measures to protect them against illegal forced evictions’; ‘States shall implement measures to enable older persons to participate actively and productively in their community and to develop their capacities and potentialities’; ‘States shall prepare and enforce appropriate and effective

³⁴ See e.g. M. Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide*, McGill-Queen's University Press, 2014, p. 189 ff.

³⁵ See M. Somerville, *Death of pain: pain, suffering, and ethics. Death Talk: The Case Against Euthanasia and Physician-assisted Suicide*, Montreal: McGill-Queen's University Press; 2001:218-30.

mechanisms to prevent abuse and strengthen the capacity of older persons to fully understand existing treatment options and their risks and benefits’, and ‘States shall design and implement comprehensive-care oriented intersectoral public health policies that include health promotion, prevention and care of disease at all stages, and rehabilitation and palliative care for older persons, in order to promote enjoyment of the highest level of physical, mental and social well-being’. Article 34 specifically asserts that ‘The Conference of States Parties, the principal organ of the Follow-up Mechanism, comprises the States Parties to the Convention [and shall] ... promote the exchange of experiences and best practices as well as technical cooperation among States Parties, with a view to ensuring the effective implementation of this Convention’. Article (4) speaks to the need for resources so older persons can exercise their rights: ‘States Parties adopt, to the full extent of their available resources and commensurate with their level of development, such measures as they consider necessary in the framework of international cooperation to progressively achieve in accordance with domestic law the full realization of economic, social, and cultural rights, without prejudice to such obligations as may be immediately applicable under international law’.

As may be seen, Article (4) also encompasses the need for ‘international cooperation’. The need for international action is also, however, indirectly addressed in Article (36) which states: ‘States Parties may consult the Inter-American Commission on Human Rights on questions related to the effective application of this Convention. They may also request the Commission’s advisory assistance and technical cooperation to ensure effective application of any provision of this Convention. The Commission will, to the extent that it is able, provide the States Parties with the requested advisory services and assistance’.

9. Final Remarks.

Referring to the ICROP as a case study, this paper shows a strategy of building a right to palliative care through the consideration of a diversity of normative tools and opinions to delineate the extent to which they encompass features of a right to palliative care. Other international legal documents could have been chosen for such an analysis: for example, the ICESCR Committee’s General Comment on the right to health, stating that the ‘core obligations’ of all signatory nations, irrespective of resources, comprise duties to ensure access to health facilities, goods and services on a non-discriminatory basis (including analgesics and the adoption and implementation of national pain and palliative care policies), to deliver essential drugs, as defined by the WHO, and to embrace and enforce a national public health strategy. The ICESCR Committee’s General Comment also addresses features such as education and access to information regarding the main

health issues in the community, including devices of preventing and controlling them, and suitable training for health personnel, including education on health and human rights, to cite just a few examples.

Debate over the values encompassed in the ICROP and in a right to palliative care will continue. Indirectly, this is suggested by the Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, where a clause regarding a right to palliative care was dropped, owing to some drafters' fear that palliative care could be confused with euthanasia.³⁶ Again, it is indirectly suggested by the fact that rights derived from the law of negligence and elder abuse have emerged only during the last two decades.³⁷ Moreover and more significantly, it is also suggested by the difficulties in introducing a rights discourse into the context of patients with life limiting illnesses. In this regard, it is worth mentioning that one argument proposed by rights sceptics is that while the rights that are encompassed in the International Covenant on Civil and Political Rights (ICCPR) (including the right to free speech and the right to assembly) are appropriate, the rights articulated in the International Covenant of Economic, Social and Cultural Rights (ICESCR) (including the right to health) are stripped of meaning by the inequality of resources and the relative inability of struggling states to afford to provide such rights.³⁸ Some theorists insist that only civil and political rights are truly human rights, whereas socio-economic 'rights' are merely desirable goals dressed up in the more powerful rhetoric of rights.³⁹ Such critics, like Maurice Cranston, argue that if the objects of socio-economic rights were provided to everyone, it would impose outrageous costs on society.⁴⁰ Clearly, these are all issues relevant to a right to palliative care. Therefore, we can anticipate that the achievement of a universal right to palliative care will take time, and that such a right

³⁶ *Amplius* Katherine Irene Pettus, 'Towards a binding convention on the rights of older persons', available at: <http://www.ehospice.com/ArticleView/tabid/10686/ArticleId/16124/language/en-GB/View.aspx> (last accessed 12 October 2015) (also stressing that the palliative care and human rights communities in Africa are working with AU member states to clarify that misconception and to ensure that palliative care language is included the final draft, slated for ratification in early 2016).

³⁷ See Katherine Irene Pettus, *op. ult. cit.*

³⁸ See e.g. Marco Odello and Francesco Seatzu, *The UN Committee on Economic, Social and Cultural Rights: The Law, Process and Practice* (Routledge 2012), ch. I; Chisanga Puta-Chekwe and Nora Flood, 'From Division to Integration: economic, Social and cultural Rights as Basic Human Rights', in Isfahan Merali and Valerie Oosterveld (eds.), *Giving Meaning to Economic, Social, and Cultural Rights* (University of Pennsylvania Press 2001), p. 39 ff.

³⁹ See, in addition to the authors quoted in footnote 34 above, Matthew Craven, *The International Covenant on Economic, Social and Cultural Rights* (Oxford University Press 1995) 28 ff; Manisuli Ssenyonjo, *Economic, Social and Cultural Rights in International Law* (Hart publishing 2009) chp. I; and Yeshanew Sisay Alemahu, *The Justiciability of Economic, Social and Cultural Rights in the African Regional Human Rights System* (Intersentia 2013) ch I.

⁴⁰ See M. Cranston, *What are Human Rights?*, London: Bodley Head, 1973, p. 12.

will always be a work in progress, continually under construction.⁴¹ Nevertheless, the growing personal experience of terminally ill patients of different ages and backgrounds around the globe with the complex issues arising from non-curative treatments might generate further human rights movements paralleling that of older persons - movements resulting in additional documents encompassing the values of a right to palliative care. In time, we may discover through continual analysis of such documents that everyone can indeed exercise his or her right to palliative care.⁴²

⁴¹ *Amplius* Gitanjali Batmanabane, 'Why patients in pain cannot get "God's own medicine?', (2014) 5 (2) *J Pharmacol Pharmacother*, pp. 81-82; Gwyther L1, Brennan F, Harding R., 'Advancing palliative care as a human right', (2009) 38 (5) *J Pain Symptom Manage*, pp. 767-74.

⁴² For a thorough discussion of the right to palliative care in relation to terminally ill children, see e.g. Jones E, Wolfe, Is there a "right way" to provide pediatric palliative care?, (2014) 17(5) *J Palliat Med.*, pp. 500-1; Downing J., Marston J, Muckaden M. Boucher S, Cardoz M, Nkosi B, Steel B. Talawadekar P, Tilve P 'Transforming children's palliative care-from ideas to action: highlights from the first ICPCN conference on children's palliative care', *Ecancermedicalscience*, p. 415 ff.