



THE INTER-AMERICAN System

as a Tool for Ensuring Access
to **Pain Relief**
and **Palliative Care**

DIANA GUARNIZO PERALTA

A Toolkit for Activists
and Health Professionals

THE INTER-AMERICAN AS A TOOL FOR ENSURING ACCESS TO PAIN RELIEF AND PALLIATIVE CARE

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ABBREVIATIONS AND ACRONYMS

ACHR

American Convention on Human Rights

Convention on Older Persons

Inter-American Convention
on Protecting the Human Rights
of Older Persons

OAS

Organization of American States

UN

United Nations

WHO

World Health Organization

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INTRODUCTION

This document is aimed at medical personnel, civil society organizations, policy makers, and anyone interested in addressing the issue of palliative care from a human rights perspective. Although for years palliative care was confined to a strictly medical analysis, in recent times the international community and United Nations bodies have recognized palliative care as a human rights issue. This document seeks to demonstrate the many linkages between palliative care and human rights in terms of both the conception and the protection of palliative care.

We hope this report serves as a useful tool for the medical community, patients, and patients' families throughout the American continent who seek legal and human rights arguments to facilitate access to more humane end-of-life care, as well as for litigants and human rights activists who wish to protect and guarantee a life without pain for patients, including during their last days of life.

This report was written by Diana Guarnizo, a researcher at the Center for the Study of Law, Justice and Society (Dejusticia). Research assistance was provided by Carlos Juliano Simoes-Ferreira, and comments were provided by Isabel Pereira and Sergio Chaparro, researchers at Dejusticia, as well as Liliana de Lima, executive director at the International Association for Hospice and Palliative Care. The publication of this report was made possible through the financial support of the Open Society Foundations.



WHAT IS PALLIATIVE CARE?

According to the World Health Organization, 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. (WHO 2002, p. 84)

Palliative care

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy*

or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
(ibid.)

Although palliative care originally emerged as a component of cancer treatment, the World Health Assembly's resolution on palliative care (Resolution 67.19), adopted in May 2014, recognizes the need for palliative care in all cases of chronic or potentially lethal diseases, such as patients living with HIV or multidrug-resistant tuberculosis.¹

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The resolution also recognizes that palliative care should be applied according to the individual needs of the patient and across all age groups, particularly the elderly and children. Indeed, people over the age of sixty-five increasingly suffer from terminal and chronic disease. As a result, access to palliative care is urgently required for this group (FXB Center for Health and Human Rights and Open Society Foundations 2013, p. 54).

In addition, children who suffer from terminal illness require care that allows them to alleviate their pain and enjoy the best life possible until death. According to WHO, palliative care for children requires a "broad multidisciplinary approach that includes the family and makes use of available community resources," including in cases of limited resources. Such care can be administered "in tertiary care facilities, in community health centres and even in children's homes" (Worldwide Palliative Care Alliance and WHO 2014, p. 6).

1 World Health Organization, *Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course*, 67th World Health Assembly Resolution WHA67.19 (2014).

2.



PALLIATIVE CARE IN THE AMERICAS

The Americas is believed to be home to 13% of the world's population in need of palliative care, with 365 adults for every 100,000 inhabitants in need of care for alleviating pain and managing symptoms (Worldwide Palliative Care Alliance and WHO 2014, p. 97). The populations most in need of such care are the elderly, children, cancer patients, HIV/AIDS patients, and patients suffering from other chronic illnesses. Despite the growing demand for palliative care, the availability of opioids is low in Latin America, and the region holds among the lowest rankings in the world in terms of palliative care's availability, accessibility, and quality.

The elderly

Latin America's demographic profile is changing at a rapid pace. While in 2010 just 10% of the region's population was over sixty years old, 25.4% of the population is projected to be in this age group by 2050 (Economic Commission for Latin America and the Caribbean 2015, p. 36). Seniors suffer more frequently from degenerative and chronic diseases than do other age groups, which increases their need for comprehensive care with a focus on palliative care (*ibid.*, p. 54).

Children

According to figures from the Pan American Health Organization and WHO, for 2012 approximately 29,000 children and adolescents under the age of fourteen were diagnosed with cancer in the Americas, with leukemia being the most common form (Globocan 2012). The increase in chronic illness among this population group poses a challenge for health systems in the region, which should ensure the availability of palliative care systems according to their populations' needs.

Low availability and unequal access to opioids

The provision of palliative care includes the administration of pain-relieving medicines, especially opioids. Despite the fact that fourteen medicines used for palliative care are listed in WHO's Model List of Essential Medicines (WHO 2015), three of which are essential for pain relief (morphine, hydromorphone, and oxycodone), and although their manufacturing costs are relatively low, 80% of the world's population lacks adequate access to these medicines. Ninety percent of the globe's opioid consumption is concentrated in developed countries, including Australia, Canada, New Zealand, the United States, and some European countries (Global Commission on Drug Policy 2015).

Data for the Americas reveal low levels of morphine consumption, which, considering the population's epidemiological profile, suggests unmet pain relief needs. Global consumption of controlled substances, such as morphine, is monitored on a regular basis by the International Narcotics Control Board. Discounting Canada and the United States—whose average consumption levels of 97.5 and 79.8 mg per capita, respectively, are far higher than the global average of 6.27 mg per capita—just two countries (Barbados and Argentina) are above the world's average; seventeen of the region's countries have consumption levels under 2 mg per capita (Pain and Policy Studies Group/WHO Collaborating Center 2015).

Low levels of accessibility and low quality of palliative care

Except for Canada and the United States, countries on the American continent exhibit a serious lag in terms of the availability, quality, and regulation of palliative care. According to *The Quality of Death Index*—an index created by the Economist Intelligence Unit to rank eighty countries on the availability, affordability, and quality of palliative care on a scale from 1 to 100 according to twenty indicators—Latin American countries fall short in all areas. While Chile ranks highest, followed by Costa Rica, Panama, and Argentina, countries such as Cuba, Uruguay, Ecuador, Brazil, Mexico, Venezuela, and Puerto Rico hold scores between 40 and 50 out of 100. The lowest scores are held by Peru, Colombia, Guatemala, and the Dominican Republic (Economist Intelligence Unit 2015).

Country in the Americas	Rank among the eighty countries studied	Score
United States	9	80.8
Canada	11	77.8
Chile	27	58.6
Costa Rica	29	58.6
Panama	31	53.6
Argentina	32	52.5
Cuba	36	46.8
Uruguay	39	46.1
Ecuador	40	44.0
Brazil	42	42.5
Mexico	43	42.3
Venezuela	45	40.1
Puerto Rico	46	40.0
Peru	49	36.0
Colombia	68	26.7
Guatemala	74	20.9
Dominican Republic	75	17.2

Source: Economist Intelligence Unit (2015).

3.



PALLIATIVE CARE AND HUMAN RIGHTS

Although palliative care originally emerged within the medical context, today access to such care is recognized as a human rights issue. In recent years, WHO, coalitions of experts, and civil society organizations working on the right to health and human rights have called attention to this issue in international forums, emphasizing that palliative care not only offers dignity to patients in situations of suffering but also deserves recognition as a human right enshrined and protected in regional and international human rights law (Open Society Foundations 2011). In 2014, the World Health Assembly's Resolution 67.19 recognized that "access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, ... contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being."²

Within the United Nations (UN) system, various Special Rapporteurs³ and treaty monitoring bodies⁴ have also recognized the multiple connections between access to palliative care and the enjoyment of human rights explicitly enshrined in key human rights treaties. Through a range of documents, these Special Rapporteurs have concluded that the lack of access to adequate palliative care may constitute a violation of the right to be free from torture and other cruel, inhuman, and degrading

2 *Ibid.*

3 Special Rapporteurs are independent experts with high technical competence and moral standing who are chosen by the UN Human Rights Commission with the aim of promoting or monitoring a particular right or topic.

4 Treaty monitoring bodies are collegiate bodies established to monitor state parties' compliance with international human rights treaties. There are currently nine treaty bodies, five of which are authorized to receive and examine individual complaints on alleged human rights violations.

treatment; the right to life; the right to health; the right to information; and the right to be free from discrimination.

With regard to the link between palliative care and the *right to be free from torture and other cruel, inhuman, and degrading treatment*,⁵ Special Rapporteur on Torture Manfred Nowak has stated 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.”⁶ Moreover, in a joint letter written by Manfred Nowak and Special Rapporteur on the Right to Health Anand Grover, directed to the Commission on Narcotic Drugs, the authors explain that “[t]he failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment.”⁷

There are also many linkages between palliative care and the *right to enjoy the highest attainable standard of physical and mental health*.⁸ The UN Committee on Economic, Social and Cultural Rights has established that a comprehensive approach to the right to health should include “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”⁹ Moreover, it establishes that “States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services.”¹⁰

The committee has also defined the duty to “provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs,”¹¹ as a basic health obligation.¹² At least fourteen palliative care medicines are currently on WHO’s essential medicines list (WHO 2013). In this respect, the Special Rapporteur on the Right to Health has explained that

many countries have failed to adapt their drug control systems to ensure adequate medication supply ... That constitutes an ongoing infringement of the right to health, as the Committee on Economic, Social and

5 International Covenant on Civil and Political Rights, art. 7.

6 United Nations (UN), *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak*, UN Doc. A/HRC/10/44 (2009), para. 72.

7 *Letter to the Commission on Narcotic Drugs from UN Special Rapporteurs*, December 10, 2008. <https://www.hrw.org/news/2008/12/10/un-human-rights-experts-call-upon-cnd-support-harm-reduction>.

8 International Covenant on Economic, Social and Cultural Rights, art. 12(1).

9 UN Committee on Economic, Social and Cultural Rights, *General Comment 14: The Right to the Highest Attainable Standard of Health (Art. 12)*, UN Doc. E/C.12/2000/4 (2000), para. 25.

10 *Ibid.*, para. 34.

11 *Ibid.*, para. 43(d).

12 With regard to this basic obligation, the Committee on Economic, Social and Cultural Rights has stated that “a State party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations set out in paragraph 43 above, which are non-derogable.” *Ibid.*, para. 47.

*Cultural Rights has elaborated that access to essential medicines is a minimum core obligation of the right, and States must comply immediately with this non-derogable obligation regardless of resource constraints.*¹³

Palliative care also has a relationship with the *right to information*,¹⁴ which is understood as an essential element of the right to health.¹⁵ In this respect, the Special Rapporteur has emphasized that patients should be able to make autonomous decisions regarding their process of dying, which includes “choices about access to adequate pain relief and other necessary interventions, location of death, and the ability to refuse treatment designed to prolong life when it is not desired by the patient,” as well as “clear, candid and non-judgmental discussion with medical practitioners, who should be adequately trained to deal with these delicate issues in order to enable older persons to ‘die with dignity.’”¹⁶

Finally, it is important to highlight the connections between palliative care and the *right to freedom from discrimination*.¹⁷ With regard to age-based discrimination, the Committee on Economic, Social and Cultural Rights has noted that “the range of matters in relation to which such discrimination can be accepted is very limited”¹⁸ and that states should “eliminate any discriminatory legislation and ... ensure the relevant budget support.”¹⁹ In its General Comment 14, the committee emphasizes that “[i]n particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services.”²⁰

At the regional level, the Inter-American Convention on Protecting the Human Rights of Older Persons (hereinafter “Convention on Older Persons”) has been at the forefront of the recognition of

13 UN, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, UN Doc. A/65/255 (2010), para. 41.

14 International Covenant on Civil and Political Rights, art. 19(2).

15 In General Comment 14, the Committee on Economic, Social and Cultural Rights recognizes access to information as an essential component of the right to health; such access “includes the right to seek, receive and impart information and ideas concerning health issues.” UN Committee on Economic, Social and Cultural Rights, *General Comment 14*, *supra* note 9, para. 12(b)(iv).

16 UN, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover, UN Doc. A/HRC/18/37 (2011), para. 59.

17 International Covenant on Civil and Political Rights, arts. 2, 4, 24; International Covenant on Economic, Social and Cultural Rights, arts. 2, 10(3).

18 UN Committee on Economic, Social and Cultural Rights, *General Comment 6: The Economic, Social and Cultural Rights of Older Persons*, UN Doc. E/C.12/1995/16/Rev.1 (1995), para. 12.

19 *Ibid.*, para. 18.

20 UN Committee on Economic, Social and Cultural Rights, *General Comment 14*, *supra* note 9, para. 34.

palliative care as a human rights issue by being the first multilateral human rights treaty to expressly recognize states' duty to take steps to ensure that older persons have access to comprehensive care, including palliative care (see section 5.1).

The recognition of palliative care as a human rights issue unlocks a new set of possibilities for demanding palliative care and ensuring its protection at both the political and legal level. In political terms, associations of patients requiring palliative care, or any other civil society organization, can demand the state's compliance with its duties in this area. In legal terms, patients' associations can utilize human rights tools to hold the state accountable for its actions or inactions before judicial and quasi-judicial bodies at the international level. The following sections explore the legal possibilities offered by the inter-American human rights system in this regard.

4.



THE INTER-AMERICAN HUMAN RIGHTS SYSTEM

The inter-American human rights system is the regional system for protecting human rights in the Americas and functions within the institutional framework of the Organization of American States (OAS). The system's origins date back to the adoption of the American Declaration on the Rights and Duties of Man during the Ninth International Conference of American States, held in Bogotá, Colombia, in 1948. The declaration recognizes all persons' rights to human dignity, to life, to equality, to freedom of religion and opinion, to health, to education, to work, and to the benefits of culture.

In November 1969, during the Inter-American Specialized Conference on Human Rights, held in San José, Costa Rica, delegates from OAS member states drafted the American Convention on Human Rights (ACHR), which entered into force on July 18, 1978. The convention reinforces the protection of human rights and establishes a mechanism for lodging individual petitions to denounce violations of the convention by a state party.

The inter-American human rights system consists of two main organs: the Inter-American Commission on Human Rights, created in 1959 and headquartered in Washington, DC, and the Inter-American Court of Human Rights, created in 1979 and headquartered in San José, Costa Rica. While the Commission is responsible for reviewing individual complaints and sometimes passing them along to the Court, the Court is charged with deciding on a case's merits, receiving evidence, and issuing final decisions that are binding on states.

The Commission also issues precautionary measures, monitors the human rights situations of OAS member states, and analyzes priority issues for the region. The Court, for its part, may issue provisional measures in cases under review, as well as advisory opinions when requested by a member state or specialized organ of the OAS.

5.



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THE INTER-AMERICAN HUMAN RIGHTS SYSTEM AND ACCESS TO PALLIATIVE CARE

5.1 “Direct” protection for access to palliative care

The inter-American human rights system has not been immune to regulatory developments regarding access to palliative care. The Convention on Older Persons, adopted by OAS member states on June 15, 2015, is a global pioneer in the guarantee and protection of access to palliative care. This convention is the first multilateral human rights treaty to expressly require states to take steps to ensure older people’s access to comprehensive care, including palliative care (art. 6). The convention acknowledges the various linkages between access to palliative care and the rights to life (art. 6), to give free and informed consent on health matters (art. 11), to receive long-term care (art. 12), and to health (art. 19).

The table below outlines the articles in the Convention on Older Persons that relate to palliative care.

The Convention on Older Persons has not yet entered into force, though it is expected to do so soon. The status of countries’ signatures and ratifications can be accessed [here](#).

**Inter-American Convention on Protecting the Human Rights of Older Persons:
Provisions relating to palliative care**

<p>Article 2 Definition of palliative care</p>	<p>“Palliative care’: 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. 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.”</p>
<p>Article 6 Right to life and dignity in old age</p>	<p>“States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care.”</p>
<p>Article 11 Right to give free and informed consent on health matters</p>	<p>“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.”</p>
<p>Article 12 Right of older persons receiving long-term care</p>	<p>“e) Adopt appropriate measures, as applicable, to ensure that older persons receiving long-term care also have palliative care available to them that encompasses the patient, their environment, and their family.”</p>
<p>Article 19 Right to health</p>	<p>“States Parties 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. To give effect to this right, States Parties undertake to:</p> <p>...</p> <p>j) Promote and strengthen research and academic training for specialized health professionals in geriatrics, gerontology, and palliative care.</p> <p>...</p> <p>l) Promote the necessary measures to ensure that palliative care services are available and accessible for older persons, as well as to support their families.</p> <p>m) Ensure that medicines recognized as essential by the World Health Organization, including controlled medicines needed for palliative care, are available and accessible for older persons.”</p>

5.2 “Indirect” protection for access to palliative care

Although the ACHR does not have specific provisions on palliative care, it is possible to conclude that it provides implicit and indirect protection for such care, to the extent that the Inter-American Court’s jurisprudence has protected the rights to a dignified life, to health, to freedom from cruel, inhuman, and degrading treatment, to information, and to freedom from discrimination.

Right to be free from cruel and inhuman treatment

Several instruments of the inter-American system prohibit cruel, inhuman, and degrading treatment.²¹ Moreover, the Inter-American Court has developed extensive jurisprudence in this respect. It has established that

*the infringement of the right to physical and psychological integrity of the human person is a type of violation which has a varying connotation and which encompasses torture and other types of mistreatment or cruel, inhuman, or degrading treatment whose physical and psychological consequences may have different degrees of intensity according to the extrinsic and intrinsic factors which should be proved in each specific situation.*²²

In other words, even in the absence of injuries, an individual’s personal characteristics and perception of reality can increase his or her suffering and may therefore be relevant when it comes to determining the existence of cruel, inhuman, or degrading treatment.

The Court has also established that, in certain cases, the absence of medical attention can constitute cruel and inhuman treatment. In *Vera Vera v. Ecuador*, the failure to provide medical attention to a prisoner caused a painful deterioration in his health that led to his death. As the Court argued, given the state’s obligation to offer medical attention to individuals who are under its custody, these actions constitute inhuman and degrading treatment within the meaning of article 5(2) of the ACHR.²³

21 Organization of American States (OAS), American Declaration of the Rights and Duties of Man, art. 1; OAS, American Convention on Human Rights, arts. 5(1), 5(2); OAS, Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women (Convention of Belém do Pará), arts. 4(b), 4(d); OAS, Inter-American Convention to Prevent and Punish Torture, arts. 1, 6, 7.

22 Inter-American Court of Human Rights, *Ximenes Lopes v. Brazil*, Judgment of July 4, 2006 (Merits, Reparations and Costs), para. 127; Inter-American Court of Human Rights, *Loayza Tamayo v. Peru*, Judgment of September 17, 1997 (Merits), para. 57.

23 Inter-American Court of Human Rights, *Vera Vera v. Ecuador*, Judgment of May 19, 2011 (Preliminary Objections, Merits, Reparations and Costs), para. 78.

Right to life

The right to life is enshrined in various instruments of the inter-American system.²⁴ The Inter-American Court has established that the right to life comprises not only the right not to be arbitrarily deprived of one's life "but also the right that [individuals] will not be prevented from having access to the conditions that guarantee a dignified existence."²⁵ For the state, this implies not only the duty to refrain from depriving a person of life arbitrarily (the duty to respect) but also the duty to adopt all appropriate measures to protect and preserve the right to life (the duty to protect).²⁶ In cases where people were infected with HIV due to negligent health services and where the state failed to adequately supervise these services, thus permitting the violation of the right, the Commission and Court have both recognized that these actions, which seriously affected individuals' health and lives, involved a violation of the duty to protect the right to life in accordance with article 4 of the ACHR.²⁷

Right to health

The right to health is explicitly protected in various instruments in the inter-American system.²⁸ Given that this right cannot be protected through the individual complaint mechanism,²⁹ the Court has protected it indirectly by linking it to the right to life (art. 4 of the ACHR)³⁰ and, more recently, to the duty to progressively realize economic, social, and cultural rights (art. 26 of the ACHR).³¹ In this way, the Court has established state responsibility not only in terms of the need to supervise the provision of health services—whether such services are offered by public or private entities (the

24 OAS, American Declaration of the Rights and Duties of Man, art. 1; OAS, American Convention on Human Rights, art. 4; OAS, Convention of Belém do Pará, art. 4(a).

25 Inter-American Court of Human Rights, *Villagrán Morales et al. v. Guatemala*, Judgment of November 19, 1999 (Merits), para. 144.

26 Inter-American Court of Human Rights, *Pueblo Bello Massacre v. Colombia*, Judgment of January 31, 2006 (Merits, Reparations and Costs), para. 120.

27 Inter-American Commission on Human Rights, *Luis Rolando Cuscul Pivaral et al. (Persons Living with HIV/AIDS) v. Guatemala*, March 7, 2005, Report No. 32/05, Petition 642/03 (Admissibility), para. 44; Inter-American Court of Human Rights, *Gonzales Lluy et al. v. Ecuador*, Judgment of September 1, 2015 (Preliminary Objections, Merits, Reparations and Costs), para. 191.

28 OAS, American Declaration of the Rights and Duties of Man, art. XI; Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador), art. 10.

29 Protocol of San Salvador, art. 19(6).

30 Inter-American Court of Human Rights, *Xákmok Kásek Indigenous Community v. Paraguay*, Judgment of August 24, 2010 (Merits, Reparations and Costs), paras. 203–208, 217.

31 See Inter-American Court of Human Rights, *Suárez Peralta v. Ecuador*, Judgment of May 21, 2013 (Preliminary Objections, Merits, Reparations and Costs), concurring opinion of Judge Eduardo Ferrer Mac-Gregor Poisot.

duty to protect)³²—but also the need to provide health care, particularly for vulnerable populations such as children (the duty to guarantee).³³

In a case centering on a young patient infected with HIV through a blood transfusion, where the state was unable to adequately exercise control over these transfusions, the Court further developed the state's duty to guarantee. Although the Court did not find a violation of the right to health, it ordered the state to provide the patient with adequate medical and psychological care, as well as the necessary medications. The Court emphasized that these health services must be free, prompt, timely, adequate, and effective.³⁴

While the Inter-American Court has not specifically referenced the right to health in the context of palliative care, the UN Committee on Economic, Social and Cultural Rights has made various pronouncements in this respect.³⁵ Moreover, the Convention on Older Persons establishes that states must commit, as part of the right to health of older persons, to promoting “the necessary measures to ensure that palliative care services are available and accessible for older persons, as well as to support their families.”³⁶

Right to information

The right to information is enshrined in article 13 of the ACHR, as well as several other instruments of the inter-American system.³⁷ In many of its rulings, the Inter-American Court has established that freedom of thought and expression includes the right to “seek” and “receive” information.³⁸ This means that all individuals have the right not just to express their ideas but also to request access to information that is in the hands of the state, provided there are no legitimate restrictions on this information. This right has both an individual and a social dimension, protecting the individual's right to freely express and impart his or her opinions, as well as society's right to receive and know the thoughts of others.³⁹

32 Inter-American Court of Human Rights, *Albán Cornejo et al. v. Ecuador*, Judgment of November 22, 2007 (Merits, Reparations and Costs), para. 119; Inter-American Court of Human Rights, *Suárez Peralta*, *supra* note 31, paras. 132, 154; Inter-American Court of Human Rights, *Ximenes Lopes*, *supra* note 22, para. 141.

33 Inter-American Court of Human Rights, “*Juvenile Reeducation Institute*” v. *Paraguay*, Judgment of September 2, 2004 (Preliminary Objections, Merits, Reparations and Costs), para. 161.

34 Inter-American Court of Human Rights, *Gonzales Lluy*, *supra* note 27, para. 359.

35 UN Committee on Economic, Social and Cultural Rights, *General Comment 14*, *supra* note 9, paras. 25, 34.

36 OAS, Inter-American Convention on Protecting the Human Rights of Older Persons, art. 19(1).

37 OAS, American Convention on Human Rights, art. 13; OAS, American Declaration of the Rights and Duties of Man, art. IV; OAS, Declaration of Principles on Freedom of Expression, principles 2–4.

38 Inter-American Court of Human Rights, *Claude Reyes et al. v. Chile*, Judgment of September 19, 2006 (Merits, Reparations and Costs), para. 77.

39 Inter-American Court of Human Rights, *Ivcher Bronstein v. Peru*, Judgment of February 6, 2001 (Merits, Reparations and Costs), para. 146; Inter-American Court of Human Rights, *Herrera Ulloa v. Costa Rica*, Judgment of July 2, 2004 (Preliminary Objections, Merits, Reparations and Costs), para. 108; Inter-Amer-

Although the Court has protected this right, generally with the aim of ensuring access to information in the state's possession, it has also referred to this right in order to allow patients to access information that is relevant to their health. For example, in cases regarding information on how to access health services and social security, the Court has established the state's obligation of "active transparency." In other words, the state is obligated to proactively provide the public with the maximum amount of information so that people are aware of how to access health services and social security services. This information should be comprehensive, easily understood, available in simple language, and up to date.⁴⁰

In medical situations, the Court has interpreted access to information as fundamental not just for understanding the risks and benefits of medical procedures but also for authorizing such procedures to be carried out. For example, in cases of exams or screenings to determine whether a victim was subjected to sexual abuse, the Court has indicated that these procedures require the victim's "prior and informed" consent.⁴¹ The Court has also noted, in cases regarding torture and sexual violence, that the medical, psychological, or psychiatric treatment offered to victims or their families require these parties' consent, underscoring the importance of providing them with information that is clear and sufficient.⁴² In this regard, the Inter-American Commission has also noted that the performance of irreversible surgical procedures, such as sterilization, require the patient's free and informed consent.⁴³

Although neither the Court nor the Commission has elaborated on the right of access to information in the context of palliative care, it is possible to conclude that the inter-American system protects patients' right to possess all information necessary for accessing health services, including information on palliative care services, on treatments for pain management, and on the patient's diagnosis.

ican Court of Human Rights, *Ricardo Canese v. Paraguay*, Judgment of August 31, 2004 (Merits, Reparations and Costs), para. 77; Inter-American Court of Human Rights, *López Álvarez v. Honduras*, Judgment of February 1, 2006 (Merits, Reparations and Costs), para. 163.

40 Inter-American Court of Human Rights, *Furlan and Family v. Argentina*, Judgment of August 31, 2012 (Preliminary Objections, Merits, Reparations and Costs), para. 294.

41 Inter-American Court of Human Rights, *Espinoza González v. Peru*, Judgment of November 20, 2014 (Preliminary Objections, Merits, Reparations and Costs), paras. 251, 256.

42 *Ibid.*, paras. 314–315; Inter-American Court of Human Rights, *Ticona Estrada et al. v. Bolivia*, Judgment of November 27, 2008 (Merits, Reparations and Costs), para. 169; Inter-American Court of Human Rights, *Rosendo Cantú et al. v. Mexico*, Judgment of August 31, 2010 (Preliminary Objections, Merits, Reparations and Costs), para. 252; Inter-American Court of Human Rights, *Cabrera García and Montiel Flores v. Mexico*, Judgment of November 26, 2010 (Preliminary Objection, Merits, Reparations and Costs), para. 221.

43 Inter-American Commission on Human Rights, *I.V. v. Bolivia*, July 23, 2008, Report No. 40/08, Petition 270-07 (Admissibility), para. 81; Inter-American Commission on Human Rights, *María Mamérita Mes-tanza Chávez v. Peru*, October 10, 2003, Report No. 71/03, Petition 12.191 (Friendly Settlement), paras. 1, 14 (friendly settlement part 11).

Right to be free from discrimination

The right to be free from discrimination is established in article 1(1) of the ACHR, as well as other instruments of the inter-American system.⁴⁴ As explained by the Court, nondiscrimination reflects a general principle that extends to all rights contained within the convention and that obligates states to guarantee those rights “without discrimination,” and it is a basic principle of international law.⁴⁵ This principle requires the state to refrain from introducing laws that establish undue differences (*de jure* discrimination) or that produce, in practice, undue differences (*de facto* discrimination).⁴⁶

In cases where access to palliative care services is already available within the health system but where the state prohibits certain communities—such as immigrants—from using these services, it is possible to argue that the state is implementing a discriminatory policy. The Inter-American Court has noted that “the general obligation to respect and guarantee human rights binds States, regardless of any circumstance or consideration, including the migratory status of a person.”⁴⁷

With regard to the criterion of old age, the Convention on Older Persons prohibits all types of discrimination based on the age of older persons.⁴⁸ In the same vein, with regard to older persons, the Committee on Economic, Social and Cultural Rights has established states’ duty to “eliminate any discriminatory legislation and the need to ensure the relevant budget support.”⁴⁹

44 OAS, American Convention on Human Rights, arts. 1(1), 24; OAS, American Declaration of the Rights and Duties of Man, art. 2; OAS, Protocol of San Salvador, art. 3; OAS, Convention of Belém do Pará, art. 6(a); OAS, Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, arts. I(2), II.

45 The Court argues that the principle of nondiscrimination can be considered as falling within the realm of *jus cogens*. Inter-American Court of Human Rights, Advisory Opinion OC-18/03 of September 17, 2003, “Juridical Condition and Rights of Undocumented Migrants,” para. 101.

46 Inter-American Court of Human Rights, *Atala Riffo and Daughters v. Chile*, Judgment of February 24, 2012 (Merits, Reparations and Costs), para. 80.

47 Inter-American Court of Human Rights, Advisory Opinion OC-18/03, *supra* note 45, operative para. 6.

48 OAS, Inter-American Convention on Protecting the Human Rights of Older Persons, art. 5.

49 UN Committee on Economic, Social and Cultural Rights, *General Comment 6*, *supra* note 18, para. 18.



WHY AND HOW TO TAKE ACTION BEFORE THE INTER-AMERICAN HUMAN RIGHTS SYSTEM

The inter-American human rights system offers a valuable tool for protecting human rights and the principles of social justice within the region. In recent years, many human rights organizations in the region have used the inter-American system as a platform for (i) raising awareness of human rights violations or the absence of state policies that guarantee rights protections; (ii) obligating states to adopt measures to prevent the imminent violation of a human right; (iii) obligating states to provide concrete reparations with regard to a specific human rights violation; and (iv) promoting new standards for human rights protection and for guiding the conduct of public officials and health providers at the domestic level.

The inter-American system can be accessed through three main mechanisms:

1. By using the *individual petition procedure* to present a specific instance of a human rights violation.
2. By presenting a request for *precautionary measures* in light of a serious and urgent situation and to prevent irreparable harm.
3. By making use of the *other noncontentious mechanisms* of the Inter-American Commission, such as public hearings, *in loco* visits, and thematic and country reports.

6.1 How to submit a petition before the inter-American system: The individual petition procedure

Who may file a complaint?

Any person, group of persons, or legally recognized nongovernmental organization in any OAS member state may file a petition alleging the violation of a right enshrined in the ACHR or the Convention on Older Persons.⁵⁰ Thus, terminally ill individuals, their family members, palliative care organizations, and others may submit an individual petition before the system. If a third party submits the complaint on behalf of a victim, it is not necessary for the petitioner to have the victim's consent or to have a familial or friendly relationship with the victim.

The petitioner must be identified by name, nationality, profession, address, and signature. Anonymous petitions are not accepted.

Identify the victim(s)

The victim must be duly identified by his or her complete name. With regard to palliative care, it is important to point out that victims may include not only patients who suffer from a particular illness and who lack access to palliative care or pain management but also family members or caregivers of a patient, given that the absence of palliative care can have severe negative impacts on these individuals' life plans, as well as on their emotional and economic well-being.

Describe the facts

The petition must include a clear and detailed description of the facts, ideally in chronological order, including dates, places, and names in order to give the reader a clear idea of events.

Explain which domestic remedies have been exhausted

The inter-American system is a *subsidiary* system of human rights protection. In other words, its jurisdiction begins once the petitioner has exhausted available domestic remedies.⁵¹ Every country has judicial and administrative remedies for the protection of the rights to life, to health, and to access to medicines, which must be utilized prior to resorting to the international arena. Nonetheless, the petitioner does not need to exhaust all existing remedies at the domestic level—rather, just those remedies considered *adequate and effective* for protecting the right allegedly violated. There is no list establishing which remedies are adequate and effective for the protection of the right to health and access to palliative care; this must be determined in each specific case.

50 OAS, American Convention on Human Rights, art. 44; OAS, Inter-American Convention on Protecting the Human Rights of Older Persons, art. 36.

51 OAS, American Convention on Human Rights, art. 46(1)(a).

Adequate domestic remedies are those that are *legally* suitable for addressing the infringement of a right.⁵² Not all remedies are designed to guarantee the right to health or access to palliative care. Each case should determine what the adequate remedy is in accordance with the specific circumstances.

The writ of **amparo**, available in most Latin American countries, is an action or remedy, generally of a constitutional nature, that seeks the protection of an individual's fundamental freedoms. The domestic law of each country establishes the procedure for filing an **amparo**, as well as the time frame for obtaining a ruling. The Inter-American Commission has recognized the **amparo** as an ideal remedy for demanding access to certain medicines.⁵³

52 Inter-American Court of Human Rights, *Velásquez Rodríguez v. Honduras*, Judgment of July 29, 1988, para. 64; Inter-American Commission on Human Rights, *Access to Justice as a Guarantee of Economic, Social, and Cultural Rights: A Review of the Standards Adopted by the Inter-American System of Human Rights*, OEA/Ser.L/V/II.129 (2004), paras. 246–249.

53 Inter-American Commission on Human Rights, *Jorge Odir Miranda Cortez et al. v. El Salvador*, March 7, 2001, Report No. 29/01, Case 12.249.

Country	Domestic law establishing or regulating the writ of amparo
Argentina	National Constitution, article 43
Bolivia	Political Constitution of the State, articles 129 and 130
Brazil	Federal Law No. 12016 of August 7, 2009 (writ of mandamus)
Chile	Political Constitution of the Republic of Chile, article 20
Colombia	Political Constitution, article 86
Costa Rica	Political Constitution of the Republic of Costa Rica, article 48 (amended by Law No. 7128 of August 18, 1989); regulated in the Law on Constitutional Jurisdiction No. 7135 of October 11, 1989
Dominican Republic	Constitution of the Dominican Republic, article 72
Ecuador	Constitution of the Republic of Ecuador, article 88
El Salvador	Constitution of the Republic of El Salvador, article 247
Guatemala	Political Constitution of the Republic of Guatemala, article 265
Honduras	Political Constitution of the Republic of Honduras, article 183
Mexico	Political Constitution of the United Mexican States, articles 103 and 107; regulated in the Amparo Law of April 2, 2013
Nicaragua	Political Constitution of the Republic of Nicaragua, article 188
Panama	Political Constitution of the Republic of Panama, article 54
Paraguay	National Constitution of the Republic of Paraguay, article 134
Peru	Political Constitution of Peru, article 200; Law No. 23506
Uruguay	Law 16011
Venezuela	Constitution of the Bolivarian Republic of Venezuela, article 27

Effective domestic remedies are those that are *capable* of fulfilling their purpose.⁵⁴ A remedy that proves illusory in light of the country's overall conditions or the particular circumstances of a given case would not be considered effective. The Inter-American Court has noted that in cases where the courts are not independent or lack the means to carry out their decisions, where there is an unjustified delay in the decision, or when the victim is denied access to a judicial remedy, a remedy cannot be considered effective.⁵⁵

54 Inter-American Commission on Human Rights, *Access to Justice as a Guarantee of Economic, Social, and Cultural Rights*, *supra* note 52, para. 251.

55 Inter-American Court of Human Rights, Advisory Opinion OC-9/87 of October 6, 1987, "Judicial Guarantees in States of Emergency (Arts. 27(2), 25 and 8 of the American Convention on Human Rights)," Series A, No. 9, para. 24.

In the case of *Jorge Odir Miranda Cortez et al. v. El Salvador*, the Salvadoran state failed to provide antiretroviral therapy to several patients living with HIV/AIDS. The petitioners alleged that the government had violated these patients' rights to life, to health, and to development of personality. With regard to the exhaustion of domestic remedies, the petitioners had filed an *amparo* that, after two years, had still not received a decision, leading them to claim the violation of the principle of reasonable time⁵⁶ and, therefore, the lack of an *effective* domestic remedy. In this regard, the Inter-American Commission stated that

*the petitioners had access to amparo proceedings, the remedy offered by the domestic legal system in this case, and they filed for these proceedings within the time period and in the manner required. However, to date, this remedy has not proven effective in responding to the claims of alleged violation of human rights. Almost two years have elapsed since the petition was filed and no final decision has been handed down by the Salvadoran Supreme Court.*⁵⁷

The Commission concluded that the *amparo* remedy in this case was neither prompt nor simple and therefore constituted a violation of the right to effective judicial protection (art. 25 of the ACHR).⁵⁸

There are several exceptions to the requirement that domestic remedies be exhausted. The first three below are laid out in article 46(2) of the ACHR, while the last two have been established by the Court.

1. The domestic legislation of the state in question does not afford due process of law for the protection of the right(s) allegedly violated.
2. The party alleging a violation of his or her rights has been denied access to the remedies under domestic law or has been prevented from exhausting them.

This situation not only constitutes an exception to the rule requiring the exhaustion of domestic resources but also can constitute a violation in and of itself (Medina and Nash 2011, p. 35). A person with a terminal illness whose physical limitations prevent him or her from exercising a certain remedy could claim that the state failed to offer the means necessary to access judicial remedies.

56 For greater clarity on "reasonable time," see Inter-American Court of Human Rights, *Baldeón García v. Peru*, Judgment of April 6, 2006 (Merits, Reparations and Costs), para. 151.

57 Inter-American Commission on Human Rights, *Jorge Odir Miranda Cortez et al. v. El Salvador*, 2001, *supra* note 53, para. 40.

58 Inter-American Commission on Human Rights, *Jorge Odir Miranda Cortez et al. v. El Salvador*, March 20, 2009, Report No. 27/09, Case 12.249 (Merits), para. 53.

3. There has been an unwarranted delay in rendering a final judgment under the aforementioned remedies.

There is no clear rule for determining when domestic authorities' delay in resolving a complaint has ceased to be justified or when a reasonable time has passed. Generally, if a remedy's legally established time frame has been exceeded before providing a resolution, the petitioner will be exempt from having to exhaust that particular remedy. However, the Inter-American Court has established that in order to evaluate the reasonableness of the length of time of the legal proceedings, it is important to keep in mind the complexity of the issue at hand, the procedural activity of the interested party, the conduct of judicial authorities, and the impacts generated for the victim on account of the prolonged proceedings.⁵⁹

4. The petitioner is destitute and lacks the resources to obtain legal assistance.

The Court has also established that indigents are exempt from exhausting applicable domestic remedies, provided that (i) they cannot afford legal counsel, and the state does not provide it free of charge; or (ii) they cannot afford to pay for the costs of legal proceedings, and the state does not waive these fees.⁶⁰ Indigents who require palliative care and find themselves in one of these situations could arguably be exempt from the requirement to exhaust domestic remedies.

5. The petitioner is unable to obtain legal counsel due to a generalized fear in the legal community around representing that person's case.

The Court has upheld this exception in cases where, for example, lawyers in a certain geographic area refuse to accept a case out of fear that it could endanger them or their family.⁶¹ Although this situation is uncommon with regard to palliative care, it could be the case that lawyers in a particular region refuse to take on such cases out of fear of being persecuted or stigmatized by a certain sector of society. In these cases, the victim would be exempt from having to exhaust the remedies laid out under domestic law.

When filing a claim, the petitioner must indicate in the petition that domestic remedies have been exhausted or that the petitioner qualifies for one of the abovementioned exceptions. In the event that the petitioner claims an exception, the onus is on the state to demonstrate that these remedies remain to be exhausted and that they are effective and available.⁶²

⁵⁹ Inter-American Court of Human Rights, *Furlan and Family*, *supra* note 40, para. 152.

⁶⁰ Inter-American Court of Human Rights, Advisory Opinion OC-11/1990 of August 10, 1990, "Exceptions to the Exhaustion of Domestic Remedies (Arts. 46(1), 46(2)(a) and 46 (2)(b) of the American Convention on Human Rights)," para. 31.

⁶¹ *Ibid.*, para. 35.

⁶² Inter-American Court of Human Rights, *Velásquez Rodríguez v. Honduras*, Judgment of June 26, 1987 (Preliminary Objections), para. 88.

Nonduplication: Confirm that the facts of the case are not being reviewed by another international body

If the facts of the complaint have already been submitted to another international human rights mechanism, such as the individual complaint procedure of the UN Human Rights Committee or Committee on Economic, Social, and Cultural Rights, they cannot be filed before the inter-American system. Since the inter-American system's individual petition procedure is exclusive of any other international mechanism, petitioners must weigh the advantages and disadvantages of submitting their complaint before UN mechanisms versus the inter-American system.

Identify the relevant violations and connect them to the rights established in the ACHR and other relevant conventions of the inter-American system

Direct justiciability

In cases where the state has ratified the Convention on Older Persons and has accepted the Inter-American Court's jurisdiction in cases concerning the application and interpretation of this convention—and provided that the facts of the case relate to the violation of the rights of an older person—the petitioner may invoke the provisions of the Convention on Older Persons as a basis for the claim (see section 5.1). This convention protects older persons' rights to life with dignity, to free and informed consent, and to health, as well as to special rights in cases requiring long-term or palliative care.

An "older person" refers to an individual aged sixty or older. If a country's domestic laws establish an age younger or older than this, the alternative age will be respected provided that it is not above sixty-five.

In any other case, the petitioner must invoke the provisions of the ACHR as a basis for the claim.

Indirect justiciability

Individuals living in OAS member states that have not ratified the Convention on Older Persons but that have ratified the ACHR, as well as those patients who are not older persons, may invoke the provisions of the ACHR so their right to palliative care can be protected in an indirect manner.

Although the ACHR does not have specific provisions on palliative care, it is possible to conclude that the convention implicitly recognizes protection for palliative care, to the extent that ACHR-related jurisprudence has protected the rights to a dignified life, to health, to freedom from cruel, inhuman, and degrading treatment, to information, and to freedom from discrimination (see section 5.2).

The advantage of this approach is that it opens up the door for more countries to be held accountable within the inter-American system. Except for Antigua and Barbuda, the Bahamas, Belize, Canada, Guyana, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Trinidad and Tobago, the United States, and Venezuela, all OAS member states are party to the ACHR.

Show that measures could repair the damage inflicted on the victim(s)

In the event that the Inter-American Court holds the state responsible for the violations alleged in the petition, it may issue any number of measures aimed at remedying the harm caused to the victim(s). These measures can be classified as follows:

- *Compensation:* Victims can request reimbursement of the costs incurred to purchase medications and other treatments not provided by the state. Compensation can also include monetary compensation for the time and resources of caregivers who looked after the patient after the state arbitrarily denied care.
- *Restitution:* Victims may, for example, request the restitution of palliative medicines that have been confiscated by the state and are still required by the patient.
- *Rehabilitation:* The Inter-American Court has established that rehabilitation measures include not just medical and psychological treatment but also access to medicines. Such measures should be awarded both to direct victims and to their closest relatives. Rehabilitation treatment should be personalized, specialized, comprehensive, and free of charge.⁶³ While in some cases the Court has ruled that treatment should be provided free of charge through the public health system—or, in the absence of such a system, in specialized private centers⁶⁴—in other cases it has ordered the payment of a sum of money that allows the patient to acquire such treatment.⁶⁵ If a patient did not have access to palliative care, he or she can request physical and psychological therapy, as well as access to medications that improve his or her quality of life. The patient's relatives may also request access to psychological therapy to deal with the trauma associated with the patient's illness.
- *Guarantees of nonrepetition:* Victims have the right to request measures aimed at preventing future violations. With regard to access to health services, the Inter-American Court has ordered states to implement training and education programs for justice operators on the topic of patients' rights⁶⁶ and to proactively inform the public about patients' rights

63 Inter-American Court of Human Rights, *Chitay Nech et al. v. Guatemala*, Judgment of May 25, 2010 (Preliminary Objections, Merits, Reparations and Costs), para. 256.

64 Inter-American Court of Human Rights, *Manuel Cepeda Vargas v. Colombia*, Judgment of May 26, 2010 (Preliminary Objections, Merits, Reparations and Costs), para. 235; Inter-American Court of Human Rights, *Ituango Massacres v. Colombia*, Judgment of July 1, 2006 (Preliminary Objections, Merits, Reparations and Costs), operative para. 16.

65 Inter-American Court of Human Rights, *Molina Theissen v. Guatemala*, Judgment of July 3, 2004 (Reparations and Costs), paras. 58(2), 71.

66 Inter-American Court of Human Rights, *Albán Cornejo*, *supra* note 32, paras. 162–164; Inter-American Court of Human Rights, *Suárez Peralta*, *supra* note 31, paras. 206, 207.

(the obligation of active transparency).⁶⁷ In other cases, the Court has ordered states to update operational manuals in order to ensure that the parameters for forensic analyses are in line with international standards⁶⁸ and has even ordered states to undertake legislative reforms.⁶⁹ With regard to palliative care, a victim might request, for example, training courses on palliative care and human rights for health operators and public officials; the updating of treatment manuals for the terminally ill and the use of opioids; and reforms to restrictive laws that inhibit access to opioids and fail to address access to palliative care.

Time frame for submitting a petition

If domestic remedies have been exhausted and the petitioner has received a formal response, the petition before the inter-American system should be filed no later than six months after receiving this response;⁷⁰ otherwise, the petition will be deemed inadmissible on account of being filed ex-temporaneously.

67 Inter-American Court of Human Rights, *Furlan and Family*, *supra* note 40, paras. 294–295.

68 Inter-American Court of Human Rights, *González et al. (“Cotton Field”) v. Mexico*, Judgment of November 16, 2009 (Preliminary Objection, Merits, Reparations and Costs), para. 502; Inter-American Court of Human Rights, *Rosendo Cantú*, *supra* note 42, para. 242.

69 Inter-American Court of Human Rights, *Raxcacó Reyes v. Guatemala*, Judgment of September 15, 2005 (Merits, Reparations and Costs), para. 89.

70 OAS, American Convention on Human Rights, art. 46(1)(b).

6.2 Request for precautionary measures

Precautionary measures are protection measures issued by the Inter-American Commission in certain *serious and urgent* situations and when there is a *risk of irreparable harm*. These measures are regulated by article 106 of the OAS Charter, article 18(b) of the Commission's Statute, article XIII of the Inter-American Convention on Forced Disappearance of Persons, and article 25 of the Commission's Rules of Procedure.

- A *serious* situation refers to a grave impact that the state's action or omission may have on a particular individual or on the eventual effect of a decision in a case pending before the inter-American system.
- An *urgent* situation implies that the risk or threat is imminent and can materialize.
- *Irreparable harm* refers to the injury of rights that, due to their nature, cannot be repaired.

Requirements

- Precautionary measures can be used to protect individuals or groups of people as long as the beneficiary or beneficiaries may be determined or determinable through their physical location or membership in a group, people, community, or organization.⁷¹ Thus, requests for such measures must clearly indicate who the beneficiaries are or include information that allows them to be determined.
- The request must include a detailed and chronological description of the facts, as well as any other available information.
- The request must include a description of the protective measures being sought.

Requests for precautionary measures may or may not be connected to a case or petition pending before the inter-American system. In the event that the measures are related to a case pending before the Commission, the granting of such measures does not constitute a prejudgment on the case or petition.⁷²

71 Inter-American Commission on Human Rights, *Rules of Procedure*, approved during the 137th regular period of sessions, October 28–November 13, 2009, and modified in September 2011 and March 2013, art. 25(3), <http://www.oas.org/en/iachr/mandate/Basics/rulesiachr.asp>.

72 *Ibid.*, art. 25(8).

Precautionary measures issued by the Inter-American Commission in *Jessica Liliana Ramírez Gaviria v. Colombia**

Since birth, twenty-three-year-old Jessica had suffered from dystrophic epidermolysis bullosa (EB), or “butterfly skin,” a condition in which the skin is extremely fragile and falls off at the slightest touch. EB is very painful, and it produces blisters that result from friction against the skin, including friction between the inner and outer layers of skin. This incurable condition affects at least one out of every two thousand people. Currently, palliative care is the only available treatment.

When she was born, Jessica was placed under intensive care at a public hospital but did not receive a comprehensive diagnosis. Between 1993 and 2000, she remained untreated because her health insurance company refused to provide specialized treatment, arguing that it was not included in the country’s obligatory health plan. At the age of seven, after her family paid out of pocket for doctors outside her network, Jessica was diagnosed with EB; these doctors cared for her between 2000 and 2005.

In September 2006, after Jessica’s family filed a **tutela** (writ of protection of constitutional rights), a local judge ordered the health insurance company to provide Jessica with the necessary treatment. Although the company provided medical treatment for several months, in general it failed to adequately comply with the judicial order, despite various appeals processes initiated by Jessica’s family to demand compliance. Between 2010 and 2013, Jessica received medical care from a private foundation. Then, after her case was publicized in the Colombian media, the health insurance company offered Jessica medical treatment. However, this treatment was inadequate: the company failed to provide the appropriate prescription medicines, denied Jessica regular visits to the dermatologist, and failed to ensure that she received specialized medical assessments related to dermatology, gynecology, and nutrition. In 2015, Jessica’s condition worsened, and her health conditions made it impossible to receive the blood transfusion she needed.

The Commission considered Jessica’s case to be **serious** “in light of the alleged deterioration in her health and the possible impact on her rights to life and physical integrity, due to the alleged lack of permanent, specialized, and comprehensive medical care.” It also considered the case **urgent** insofar as “the passing of time, within the framework of the aforementioned health conditions and without the implementation of ... applicable health standards, could exacerbate the risks to Jessica’s life and physical integrity.” Moreover, the potential harm was considered **irreparable** since it implied possible negative effects to Jessica’s life and physical integrity.

As a result, the Inter-American Commission ordered the Colombian state to

(a) adopt the necessary measures to preserve the life and physical integrity of Jessica Liliana Ramírez Gaviria, taking into account the specific characteristics of the illness at hand, with the aim of guaranteeing her access to adequate medical care in line with the technical guidelines of the Pan American Health Organization and other applicable international standards; and (b) reach agreement on the measures with the beneficiary and her representatives.

* Inter-American Commission on Human Rights, *Asunto Jessica Liliana Ramírez Gaviria respecto de Colombia*, Resolución 42/2005, Medidas Cautelares No. 445/14, November 4, 2015. <http://www.oas.org/es/cidh/decisiones/pdf/2015/mc445-14-es.pdf>.

6.3 Noncontentious mechanisms

Public hearings

Human rights organizations, victims' organizations, and any other interested party may request a hearing of a general nature before the Inter-American Commission in accordance with article 66 of the Commission's Rules of Procedure.

These hearings offer an important opportunity to draw the Commission's attention to a particular issue within the region, as well as to hold states accountable for their actions in a specific area.

In general, hearing requests that are presented by a coalition of like-minded organizations tend to be more persuasive than those presented by a single organization or an individual. Public hearings offer an attractive venue for presenting the results of a fact-finding report that exposes a particular human rights situation. Given that hearings are public and that the government in question is invited, they can also be used as a space to call governments to account and to examine these governments' actions in response to alleged violations.

Hearings must be requested in writing to the Executive Secretariat of the Commission at least fifty days prior to the beginning of the respective session of the Commission.

The Commission holds three sessions per year, generally in April, July, and October. More detailed information can be found in the Commission's online calendar.

Country reports

The Inter-American Commission publishes country reports aimed at monitoring the human rights situation in individual countries. Civil society and human rights organizations can participate in the preparation of these reports by providing information on the fulfillment of a particular right in the country at hand. Country reports are sometimes issued after an *in loco* visit, though such a visit is not necessary for the Commission to publish a report. In many cases, for example, when a state refuses to receive a visit by the Commission, or when it is not possible to arrange a date, the Commission may prepare a country report based on information received by government authorities and civil society actors. In such cases, any organization may send relevant information to the Commission about an alleged human rights violation.

Thematic reports

The Commission also prepares reports that address specific human rights issues within the region. Although the Commission reserves the right to select the topic of each report, civil society and human rights organizations can participate in their preparation by responding to specialized questionnaires that the Commission publishes on its website.

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Although for years palliative care was confined to a strictly medical analysis, the international community and United Nations bodies have recently recognized palliative care as a human rights issue. This toolkit seeks to demonstrate the many linkages between palliative care and human rights in terms of both the conception and the protection of palliative care.

The document is aimed at medical personnel, civil society organizations, policy makers, patients and their families, and anyone interested in addressing the issue of palliative care from a human rights perspective. It is a valuable tool for all those who seek legal and human rights arguments to facilitate access to more humane end-of-life care and to guarantee a life without pain for patients, including during their last days of life.