

## **ENDING NEEDLESS SUFFERING**

Improving Palliative Care in Francophone Africa



(front cover) Patients receiving transfusions and chemotherapy at Dantec Hospital's Joliot Curie cancer ward in Senegal. © 2013 Angela Chung/Human Rights Watch

# **ENDING NEEDLESS SUFFERING**

## Improving Palliative Care in Francophone Africa

May 2015







**AFRICAN PALLIATIVE CARE ASSOCIATION** 

www.africanpalliativecare.org

ASSOCIATION SÉNÉGALAISE DE SOINS PALLIATIFS ET D'ACCOMPAGNEMENT

FÉDÉRATION INTERNATIONALE DE SOINS PALLIATIFS



HUMAN RIGHTS WATCH HRW.org



#### INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

www.iahpc.com



#### INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK

www.icpcn.org



#### PAIN & POLICY STUDIES GROUP www.painpolicy.wisc.edu

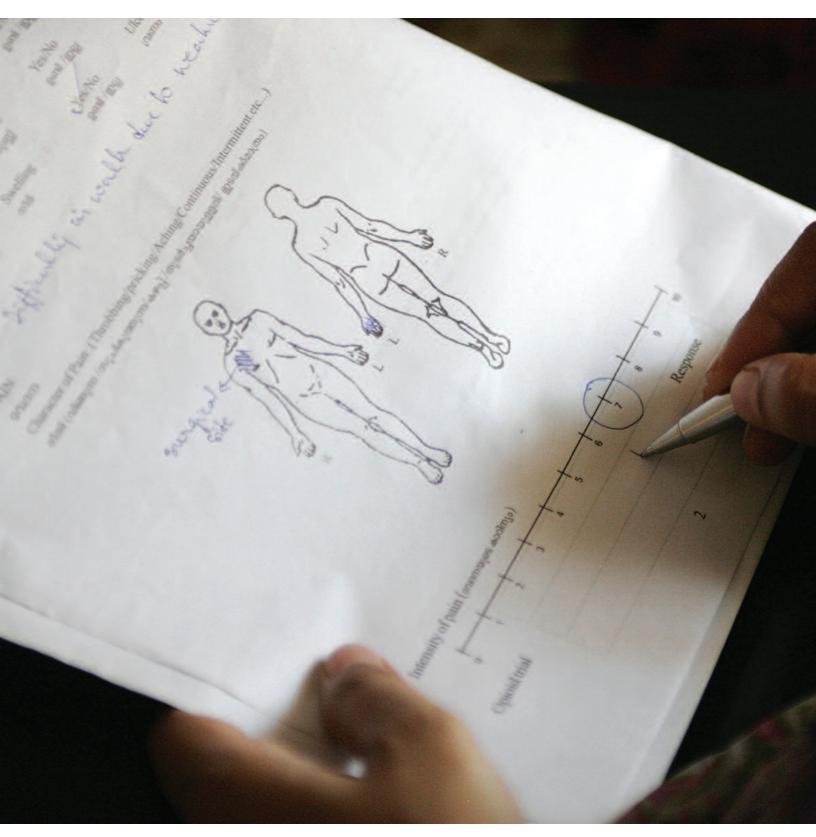


UNION FOR INTERNATIONAL CANCER CONTROL www.uicc.org



THE WORLD HOSPICE PALLIATIVE CARE ALLIANCE www.thewhpca.org

INTRODUCTION	7
PALLIATIVE CARE IN FRANCOPHONE AFRICA	9
PALLIATIVE CARE DEVELOPMENT IN FRANCOPHONE AFRICA	10
OPIOID CONSUMPTION IN FRANCOPHONE AFRICA	12
BARRIERS TO PALLIATIVE CARE IN FRANCOPHONE AFRICA Removing Barriers to Palliative Care in Francophone Africa	
DEVELOPING PALLIATIVE CARE IN FRANCOPHONE AFRICA	-
Key Recommendations in the WHA Resolution	17



A physician filling out a pain chart for a cancer patient. © 2007 Ruth Fremson/The New York Times/Redux

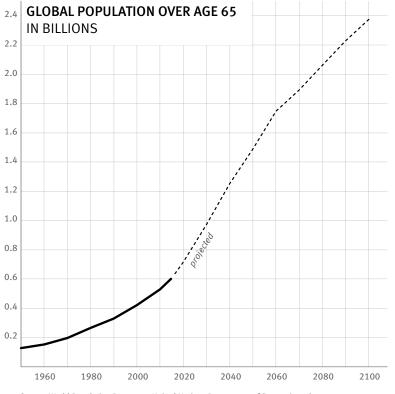


## **INTRODUCTION**

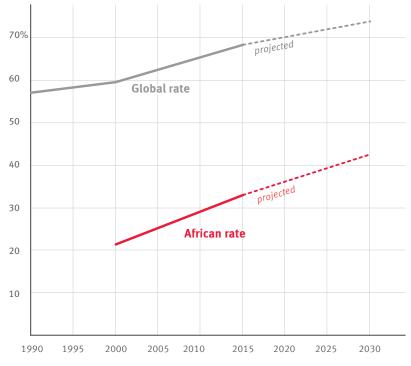
People in countries around the world are living longer, presenting health systems with a significant new challenge: caring for more and more people with one—and often several—advanced chronic illnesses, such as cancer, diabetes, dementia, or heart and lung disease. These illnesses are by far the leading cause of mortality in the world today, accounting for 63.5 percent of all deaths.<sup>1</sup>

They are also often accompanied by symptoms such as pain, shortness of breath, nausea, anxiety, and depression. If not treated properly, these symptoms can destroy the quality of life of both patients and their families. For example, Human Rights Watch has found that people with untreated severe pain often describe their pain in exactly same terms as victims of torture—that is, as so intense that they would do anything to make it stop.<sup>2</sup>

People with untreated severe pain often describe their pain in exactly same terms as victims of torture—that is, as so intense that they would do anything to make it stop. – Human Rights Watch



Source: World Population Prospects: United Nations Department of Economic and Social Affairs, Population Division.



#### NON-COMMUNICABLE DISEASES AS A PERCENTAGE OF ALL DEATHS

Sources: 2000, 2015, and 2030: Cause-Specific Mortality and Projections: World Health Organization: Health Statistics and information systems.

1990: Global Burden of Disease Data: Institute for Health Metrics and Evaluation.

While advanced, progressive chronic illnesses may often not be curable, the symptoms they cause can generally be well-controlled with inexpensive medicines and interventions. Palliative care, an emerging field of medicine, focuses on ensuring that people with life-limiting illnesses and their loved-ones can enjoy the best possible quality of life during their disease, up until their last moments.

The World Health Organization (WHO) estimates that 40 million people require palliative care at the end of life each year. Yet the availability of palliative care is limited in much of the world. A recent WHO report estimates that no palliative care services exist in 75 countries<sup>3</sup> and that around 5.5 million cancer patients and 1 million end-stage HIV/AIDS patients suffer moderate to severe pain each year without treatment.<sup>4</sup>

In 2014, the World Health Assembly, a meeting where health ministers from around world discuss pressing global health issues, took the critical step of calling on all countries to integrate palliative care into their health systems to end to this needless suffering.

Approximately 5.5 billion people, or three quarters of the world's population, live in countries with ... inadequate access to treatment for moderate to severe pain...

– International Narcotics Control Board, March 2015<sup>5</sup>



Dr. Oumar Ba, medical oncologist, and his colleague in a consultation room in Dakar, Senegal. © 2014 Dr. Oumar Ba

### Palliative Care in Francophone Africa

Palliative care provides continuity to curative medicine. Caregivers no longer feel powerless faced with the disease, and the patient, with access to relief from pain, recovers his/her dignity, hope and a better quality of life.

—Dr. Oumar BA, Medical Oncologist, Grand Yoff Hospital, Senegal, 2015.

Each year, an estimated 912,000 people, including 214,000 children, require palliative care in Francophone Africa.<sup>6</sup>

The need for this essential health service is likely to rise significantly in the coming years as the percentage of people over 65, the segment of the population most affected by chronic illnesses, is expected to more than double in Francophone Africa by 2050.<sup>7</sup>

Yet the availability of palliative care services is very limited in the region. A 2012 study, for example, found that 16 of 22 Francophone African countries do not have any healthcare providers that offer palliative care. In contrast, the same study found that nearly all Anglophone African countries had at least some palliative care services (see table I).<sup>8</sup>

The availability of morphine, a strong pain killer that is indispensable for pain management, is very limited in Francophone Africa countries. The International Narcotics Control Board, a United Nations agency, classifies each country in the region, apart from Tunisia, as having "very inadequate" morphine availability.<sup>9</sup> More than half the countries in the region for which data is available use so little morphine that it is not even sufficient to treat 5 percent of people dying in pain from cancer and AIDS each year.

## Palliative Care Development in Francophone Africa

Table I: Comparison of Palliative Care Development in Francophone and Anglophone Africa<sup>10</sup>

<b>Francophone Africa<sup>11</sup></b> WHPCA/WHO Level of Palliative Care Development				
Benin				
Burkina Faso				
Burundi				
Central African Republic				
Chad				
Comoros				
Djibouti				
Gabon				
Guinea				
Mauritania				
Niger				
Senegal+				
Тодо				
Algeria				
Democratic Republic of the Congo				
Madagascar				
Cameroon				
Congo				
Mali				
Могоссо				
Tunisia				
Côte d'Ivoire				

<b>Anglophone Africa</b> AWHPCA/WHO Level of Palliative Care Development				
	Liberia			
	Mauritius			
	Seychelles			
	Botswana			
	The Gambia			
	Ghana			
	Lesotho			
	Namibia			
	Nigeria			
	Rwanda			
	Sierra Leone			
	Sudan*			
	Swaziland			
	Kenya			
	Malawi			
	South Africa			
	Tanzania			
	Zambia			
	Zimbabwe			
	Uganda			
Cincere				

+ Since 2011, Senegal has developed two palliative care services.

\* Data was collected in 2011, prior to South Sudan's independence in September of that year.

- No known palliative care provision or initiatives to develop it
- No known palliative care provision but evidence of some initiatives to develop it
- A small number of palliative care services operational
- Multiple palliative care services operational but not integrated into the healthcare system
- Palliative care is partially integrated into the healthcare system
- Comprehensive provision of palliative care throughout the country

#### Palliative Care Development in Africa

- No known palliative care provision or initiatives to develop it
- No known palliative care provision but evidence of some initiatives to develop it
- A small number of palliative care services operational
- Multiple palliative care services operational but not integrated into the healthcare system
- Palliative care is partially integrated into the healthcare system
- Comprehensive provision of palliative care throughout the country



SOURCE: The WHO and World Wide Hospice and Palliative Care Alliance (WHPCA), "Global Atlas of Palliative Care at the End of Life," January 2014. Data was collected in 2011, prior to South Sudan's independence in September of that year.

## **Opioid Consumption in Francophone Africa**

#### Table II: Opioid Consumption Data for Francophone Africa<sup>12</sup>

Country	Estimated Annual Cancer and AIDS Deaths with Moderate to Severe Pain (2012)	Estimated Number of Terminal Cancer and AIDS Patients who:	
		Are not Receiving Ade- quate Pain Treatment (Minimum Number)	Could be treated with all Strong Opioids Con- sumed (percentage)
Burundi	6.933		
Central African Republic	7.237		
Comoros	329		
Congo	3.796		
Djibouti	848		
Guinea	5.931		
Mauritania	1.576		
Niger	5.419		
Burkina Faso	7.722	7.681	<b>&lt;</b> 1 %
Côte d'Ivoire	22.939	22.827	<1 %
Gabon	1.645	1.637	<b>&lt;</b> 1 %
Chad	10.787	10.634	1 %
Democratic Republic of the Congo	40.626	40.122	1 %
Mali	7.991	7.915	1 %
Togo	5.808	5.732	1 %
Cameroon	25.049	24.497	2 %
Madagascar	13.473	12.269	2 %
Senegal	4.832	4.757	2 %
Benin	4.568	4.402	4 %
Morocco	18.838	15.163	20 %
Algeria	17.860	13.971	22 %
Tunisia	5.921	0	124 %

Country did not report opioid consumption to the INCB during 2010-2012

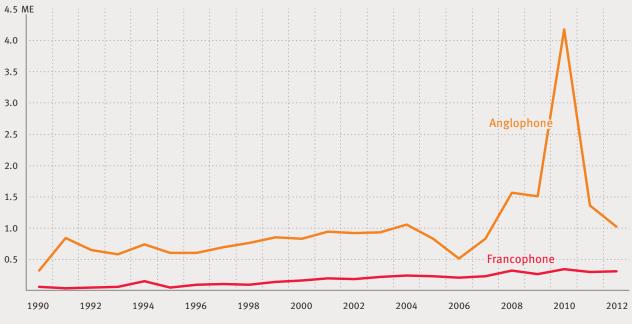
Consumption of less than or equal to 2 percent of that needed to treat all cancer and HIV/AIDS patients with pain

Consumption of between 2.1 and 5 percent of that needed to treat all cancer and HIV/AIDS patients with pain

Consumption of between 5.1 and 25 percent of that needed to treat all cancer and HIV/AIDS patients with pain

Consumption of between 25.1 and 99% percent of that needed to treat all cancer and HIV/AIDS patients with pain

Consumption of equal to or greater than 100 percent of that needed to treat all cancer and HIV/AIDS patients with pain



#### OPIOID CONSUMPTION IN MORPHINE EQUIVALENCE, 1990-2012 (MG/PERSON) COMPARISON OF FRANCOPHONE AND ANGLOPHONE COUNTRIES IN AFRICA

SOURCES:

Consumption data: International Narcotics Control Board Population: United Nations World Population Prospects, The 2012 Revision; World Health Statistics, World Health Organization ME conversion factors: WHOCC Centre for Drug Statistics Methodology Opioids included in ME metric: fentanyl, morphine, hydromorphone, oxycodone, péthidine

Pain and Policy Studies Group University of Wisconsin Carbone Cancer Center WHO Collaborating Center



## Barriers to Palliative Care in Francophone Africa

We are only at the beginning of our goal, which is to provide people experiencing the most difficult times in their lives, the opportunity to receive appropriate care nearby their families.

-Dr. Mati Nejmi, former chief of anesthesiology at the National Oncology Institute in Rabat, Morocco, 2014.<sup>13</sup>

#### The reasons for the gap between the need for palliative care and its availability are well documented. Barriers include a lack of health policies to support the development of palliative care; lack of adequate training for healthcare workers in the discipline; challenges with the

Patients and their relatives waiting outside Morocco's National Institute of Oncology in Rabat, Morocco.

supply of palliative care medicines; and controlled substance regulations that complicate prescribing and dispensing opioid analgesics, such as morphine.<sup>14</sup>

Moreover, in many Francophone African countries, providing palliative care is a relatively new challenge. Even today, many people in the region die relatively sudden deaths due to communicable diseases or trauma. However, due to advances in medical care, more and more people now succumb to long-term chronic illness or old age. Adapting healthcare systems to this new reality is a major challenge.

Even so, a number of countries, including in Francophone Africa, have shown that substantial progress can be made in developing this essential health field with low-cost, effective measures. As the WHO has noted, taking steps to address these barriers "cost[s] very little but can have a significant effect."<sup>15</sup>

#### Taking steps to address these barriers "cost[s] very little but can have a significant effect."

World Health Organization,
"Cancer Pain Relief: With a Guide to Opioid Availability,"
1996<sup>23</sup>

#### Removing Barriers to Palliative Care in Francophone Africa

**Healthcare Policy:** Many countries do not have a strategy for addressing palliative care needs as they have not yet integrated palliative care into national healthcare plans and policies on cancer or non-communicable diseases.<sup>16</sup> This is especially problematic in cancer plans because most cancer patients in low and middle income countries are diagnosed at advanced stages in the diseases and can only benefit from palliative care.

**A positive example**: In 2006, the Ministry of Health of Côte d'Ivoire released a five-year palliative care strategy. One of the few stand-alone palliative care strategies in Africa, it lays out specific steps for the government to take to improve access to this essential health service.<sup>17</sup> As Table I shows, Cote d'Ivoire was the only Francophone African country in 2011 with multiple operational palliative care services.

**Medical Education:** In many countries, healthcare workers do not receive any training in caring for patients with advanced illnesses.<sup>18</sup> Without adequate knowledge and practical experience, they become impotent witnesses to the suffering of their patients.

**A positive example**: Morocco recently amended their undergraduate medical curriculum to include palliative care. In 2015, all medical students will receive 20 hours of mandatory instruction on pain and palliative care.<sup>19</sup>

**Medicine Availability:** Overly strict regulations on controlled substances impede patients' access to opioid analgesics in many countries.<sup>20</sup> In numerous Francophone African countries, colonial-era regulations limit to seven-days the amount of time morphine can be prescribed, meaning patients in grave conditions or their relatives must make the often difficult trip to their doctor each week to pick up a new prescription. France changed this regulation in 1999, but it remains in place in many countries in the region.<sup>21</sup>

**Positive examples**: Algeria, Morocco, and Tunisia have increased their opioid prescription period from 7 to 28 days.<sup>22</sup>



#### Developing Palliative Care in Francophone Africa

It's unbearable to see your child sick and in pain.

-Momour Niang, Adama's father.

In 2014, the World Health Assembly unanimously adopted resolution WHA67.19 calling on all UN member states to integrate palliative care into national health systems.<sup>24</sup> The resolution states that it is the "ethical duty of health care professionals to alleviate pain and suffering...irrespective of whether the disease or condition can be cured." Similarly, the WHO Global Action Plan for the Prevention and Control of Non-Communicable Diseases identifies palliative care as an integral part of comprehensive care for these illnesses. Adama, a 14-year-old girl with leukemia, at Dantec Hospital in Senegal, where she got morphine syrup to relieve her pain. Adama passed away in June 2013.

© 2013 Angela Chung/Human Rights Watch

The resolution and action plan offer a road map for integrating palliative care into national healthcare systems, with recommendations regarding health and financing policies, training of healthcare workers, and access to essential medicines. The resolution also calls on the WHO to develop and update relevant clinical guidelines and provide member states technical assistance in developing palliative care services.

In the next two years, the WHO will work with member states, an ad-hoc technical expert group, and civil society organizations to implement the resolution. It is preparing a comprehensive implementation strategy for the resolution, developing new clinical and policy guidance for use by Member States, and plans to work with several Member States to create pilot projects.

These efforts provide Francophone African countries and their healthcare systems with an important opportunity to address an increasingly urgent healthcare need and make sure that their citizens can live with dignity even while living with an incurable disease. It is the ethical duty of health care professionals to alleviate pain and suffering...irrespective of whether the disease or condition can be cured.

-World Health Assembly (WHA) resolution on palliative care, May 2014.<sup>25</sup>

#### *Key Recommendations in the WHA Resolution:*

**Healthcare Policy:** Develop, strengthen and implement ... palliative care policies ... integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels....

**Education:** Aim to include palliative care as an integral component of the ongoing education and training offered to care providers... according to the following principles:(a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education...; (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses...; and (c) specialist palliative care training should be available to prepare health care professionals who will manage [patients with complex symptoms].

**Medicines Availability:** Review and, where appropriate, revise national and local legislation and policies for controlled medicines...[and] update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines....

**Funding:** Ensure adequate domestic funding and allocation of human resources... for palliative care initiatives....

<sup>1</sup> United Nations Department of Economic and Social Affairs (UNDESA) Population Division, "Changing Levels and Trends in Mortality: the Role of Patterns of Death by Cause," 2012, p. 7, http://www.un.org/esa/population/publications/levelsandtrendsinmortality/Changing%20lev-els%20and%20trends%20in%20mortality.pdf (accessed March 31, 2015).

<sup>2</sup> Human Rights Watch Report, *Please Don't Make Us Suffer Anymore: Access to Pain Treatment as a Human Right*, pp. 6-7 (New York: Human Rights Watch, 2009), http://www.hrw.org/reports/2009/03/02/please-do-not-make-us-suffer-any-more/.

<sup>3</sup> WHO and Worldwide Hospice Palliative Care Alliance (WHPCA), "Global Atlas of Palliative Care at the End of Life," January 2014, p. 36, http://www.who.int/nmh/Global\_Atlas\_of\_Palliative\_Care.pdf (accessed April 13, 2015).

<sup>4</sup> WHO Briefing Note, "Access to Controlled Medications Programme," April 2012, p. 1, http://www.who.int/medicines/areas/quality\_safety/ACMP\_BrNote\_Genrl\_EN\_Apr2012.pdf?ua=1 (accessed April 13, 2015).

<sup>5</sup> International Narcotics Control Board (INCB), "Report 2014," March 2015, p. 3, https://www.incb.org/documents/Publications/AnnualReports/AR2014/English/AR\_2014.pdf (accessed March 23, 2015).

<sup>6</sup> Calculated based on WHO's estimate of palliative care need in the Eastern Mediterranean and African region. WHO and WHPCA, "Global Atlas of Palliative Care at the End of Life," pp. 98-99.

7 See: http://esa.un.org/wpp/unpp/panel\_indicators.htm/ .

<sup>8</sup> We are not aware of any studies that have specifically investigated the reasons for the gap between Anglophone and Francophone countries although the fact that the United Kingdom was the birthplace of palliative care and that most palliative care funders, including the Diana Princess of Whales Memorial Fund, the Open Society Foundations and the US President's Emergency Fund for AIDS, have funded such initiatives in Anglophone African countries, are likely factors.

International Narcotics Control Board, "Availability of Opioids for Pain Management (2010-2012 average)," 2012, https://www.incb.org/documents/Narcotic-Drugs/Availability/total\_2010\_2012\_final.pdf\_Tunisia's use of opioid analgesics is classified as simply "inadequate".

<sup>10</sup> WHO and WHPCA, "Global Atlas of Palliative Care at the End of Life," p. 36, http://www.who.int/nmh/Global\_Atlas\_of\_Palliative\_Care.pdf (accessed April 20, 2015). T. Lynch, et al., "Mapping Levels of palliative Care Development: A Global Update," *Journal of Pain and Symptom Management*, vol. 45, no. 6, June 2013, http://www.jpsmjournal.com/article/S0885-3924(12)00334-X/pdf (accessed April 20, 2015).

<sup>11</sup> To categorize countries as Francophone or Anglophone, we looked at the prevalence of spoken French or English within each country. In countries were both languages are commonly spoken, we considered the following factors in making our determination: language officially recognized by the government; language used in government affairs; language used in educational settings; and colonial history. The level of palliative care development and/or morphine consumption within a given country was not a consideration in our determination.

<sup>12</sup> American Cancer Society, "Treat The Pain, Country Reports," http://www.treatthepain.org/country\_reports.html (accessed March 3, 2015).

<sup>13</sup> Youssef Sourgo, "Creation of the First Unit for Palliative Care in a Private Clinic in Casablanca," *Morocco World News*, June 5, 2013, http://www.moroccoworldnews.com/2013/06/93462/creation-of-the-first-unit-for-palliative-care-in-a-private-clinic-in-casablanca/ (accessed April 13, 2015).

<sup>14</sup> WHO, "Cancer Control: Knowledge into Action: WHO Guide for Effective Programmes: Module 5," 2007, p. 6, http://whqlibdoc.who.int/publications/2007/9241547345\_eng.pdf?ua=1 (accessed April 13, 2015); WHA resolution 67.19, "Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course," May 14, 2014, http://apps.who.int/gb/ebwha/pdf\_files/WHA67/A67\_R19-en.pdf (accessed April 13, 2015).

<sup>15</sup> WHO, "Cancer Pain Relief: With a Guide to Opioid Availability," 1996, p. 43-

<sup>16</sup> WHO and WHPCA, "Global Atlas of Palliative Care at the End of Life," p. 27.

<sup>17</sup> Ministère De La Sante et de l'Hygiène Publique, "Plan Stratégique National des Soins Palliatifs—2006-2010," http://www.fhi360.org/resource/plan-strategique-national-soins-palliatifs-cote-ivoire (accessed April 13, 2015).

<sup>18</sup> WHO and WHPCA, "Global Atlas of Palliative Care at the End of Life," p. 27

<sup>19</sup> Human Rights Watch interview with Dean Mohamed Adnaoui, dean of the Faculty of Medicine and Pharmacy of Rabat, Rabat, January 21, 2015.

<sup>20</sup> WHO and WHPCA, "Global Atlas of Palliative Care at the End of Life," p. 28.

<sup>21</sup> Décret no 99-249 du 31 mars 1999 relatif aux substances vénéneuses et à l'organisation de l'évaluation de la pharmacodépendance, modifiant le code de la santé publique, art. 5, XI, http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXToooooo393106&fastPos=1&fastReqId=326431723&categorieLien=id&oldAction=rechTexte\_

<sup>22</sup> MY. Achouri, et al., "Evolution de la Réglementation Pharmaceutique des opioïdes Majeurs en Algérie." http://www.saetddz.com/upload/File/6c/SALLE%20COMMISSION/16-MY%20ACHOURI%20Evolution%20de%20la%20reglementation.pdf (accessed April 10, 2015); Mati Nejmi, M.D. and Leyla Hessissen, M.D., "Moroccan Experience," *in Palliative Care to the Cancer Patient: The Middle East as a Model for Emerging Countries*, ed. Michael Silberman (New York: Nova Publishers, 2014) ; Modifiant et Complétant la Loi n° 69-54 du 26 juillet 1969, Portant Réglementation Des Substances Vénéneuses, law no. 2009-30 of 2009, art. 83, http://www.atds.org.tn/Loi2009\_30.pdf (accessed April 10, 2015).

<sup>23</sup> WHO, "Cancer Pain Relief: With a Guide to Opioid Availability," p. 43.

<sup>24</sup> WHA resolution 67.19, Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course, May 14, 2014, http://apps.who.int/gb/ebwha/pdf\_files/WHA67/A67\_R19-en.pdf (accessed April 20, 2014).

<sup>25</sup> Ibid.

AFRICAN PALLIATIVE CARE ASSOCIATION · ASSOCIATION SÉNÉGALAISE DE SOINS PALLIATIFS ET D'ACCOMPAGNEMENT FÉDÉRATION INTERNATIONALE DE SOINS PALLIATIFS · HUMAN RIGHTS WATCH · INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK · PAIN & POLICY STUDIES GROUP UNION FOR INTERNATIONAL CANCER CONTROL · THE WORLD HOSPICE PALLIATIVE CARE ALLIANCE