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ABANDONED IN AGONY

Cancer and the Struggle for Pain Treatment in Senegal



Abandoned in Agony

Cancer and the Struggle for Pain Treatment in Senegal

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Key Terms in Palliative Care and Pain Treatment

Palliative care: Healthcare that aims to improve the quality of life of people facing life-limiting illness, through pain and symptom relief, and through psychosocial support for patients and their families. Palliative care can be delivered in parallel with curative treatment, but its purpose is to care, not to cure.

Life-limiting illness: A broad range of conditions in which painful or distressing symptoms occur; although there may also be periods of healthy activity, there is usually at least a possibility of premature death.

Psychosocial support: A broad range of services such as those provided by psychologists, counselors and social workers. Many kinds of psychosocial support, such as facilitating play for hospitalized children, can be performed by volunteers.

Hospice: A specialist palliative care facility. Some hospices are residential facilities, but in Senegal, many hospices do not have inpatients. Instead, staff provide palliative care for outpatients and visit patients in the hospital or their homes.

Community-based palliative care: Also called home-based palliative care. Care performed by one or more health workers visiting the patient at home. Basic community-based palliative care services can be performed by appropriately trained community health workers, but other aspects of palliative care, such as diagnosis and opioid prescribing, can only be performed by a doctor or nurse.

Chronic pain: As used in this report, pain that occurs over weeks, months, or years, rather than a few hours or a few days. Because of its duration, moderate to severe chronic pain are typically treated with oral opioids, rather than repeated injections, especially for children and people who are emaciated by diseases such as cancer and HIV/AIDS.

Neuropathic pain: Pain caused by damaged or dysfunctional nerves. This type of pain is a common symptom of HIV and cancer. Some patients with neuropathic pain do not receive adequate relief from opioids alone and need other specialized medicines.

Level 1 analgesics: Also called basic pain medicines. Non-opioid pain medicines suitable for mild pain. These include anti-inflammatories like paracetamol (also known as acetaminophen), aspirin, diclofenac, and ibuprofen (known in Senegal as Brufen).

Level 2 analgesics: Stronger pain medications which include weaker opiates such as codeine, tramadol, trabar, buprenorphine (known in Senegal as Temgesic), and dihydrocodeine.

Level 3 analgesics: The strongest level of pain relief, which includes strong opiates such as morphine and fentanyl.

Opioid: Drugs derived from the opium poppy and similar synthetic drugs. All strong pain medicines, including morphine and pethidine, are opioids. Weaker opioids include codeine, tramadol, and dihydrocodeine.

Morphine: A strong opioid medicine and the gold standard for treatment of moderate to severe pain. Morphine is considered an essential medicine by the World Health Organization in its injectable, tablet, and oral solution formulations. Oral solution mixed from morphine powder is the cheapest formulation.

Opioid dependence: Physical dependence experienced by a patient treated with opioids over time, such that withdrawal symptoms occur if the opioid is stopped abruptly. Physical dependence is treated by gradually reducing the opioid dose. It is distinct from addiction, a pattern of behaviors including compulsive use of drugs despite harm, which is uncommon in patients receiving opioid pain treatment.



Dantec Hospital's Joliot Curie cancer ward is the only specialized institution for cancer treatment in Senegal. It is so crowded that cancer patients sit two per bed for transfusions and chemotherapy.



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Cancer and the Struggle for Pain Treatment in Senegal

BINETA'S STORY

The first signs of illness came in May 2011, when Bineta Ndeye, an eight-year-old girl from a small town in Senegal's Diourbel Region, developed stomach pain. After a few days, instead of improving, her condition worsened. She lost her appetite, lost weight, became feverish, and then started vomiting frequently. Bineta's mother told Human Rights Watch that she developed what she described as "a small ball" in her left abdominal area and that her stomach pain grew increasingly severe.

As is common in Senegal, Bineta's parents initially took her to a traditional healer who treated her with plant extracts, but without success. They then turned to modern medicine, following a common trajectory for rural dwellers in Senegal. First, they went to a local health post, staffed by only a nurse who could only examine the swelling. The nurse referred them to Diourbel Regional Hospital, where an ultrasound led to a preliminary diagnosis of neuroblastoma, one of the most prevalent forms of childhood cancer. As childhood cancers can only be treated in Dakar, Senegal's capital, Bineta's parents, who are subsistence farmers with eight children, had to raise money to travel there for final diagnosis and treatment.

During the two months that Bineta's family sought treatment in Diourbel, their daughter's severe stomach pain was left untreated. In Dakar, at the pediatric oncology unit at Dantec Hospital, Bineta finally received morphine syrup, a strong medication that is commonly used to treat moderate to severe cancer pain. Her mother told us that after taking the medication, Bineta was able to sit up and sleep peacefully for the first time in months. She was even able to play.

At Dantec, Bineta underwent chemotherapy and then surgery. Though she began a second course of chemotherapy after the operation, she was unable to complete it. Her mother told Human Rights Watch that

she could no longer afford the cost of the travel and medical treatment, and they had to return to their home region. Bineta's treatment stopped, but her pain continued.

As Bineta's mother would soon learn, Dakar is the only city in Senegal that has morphine for public medical purposes. When Human Rights Watch interviewed Bineta's mother, only Dantec hospital supplied oral morphine for outpatients. Frustrated, Bineta's mother said, "Wherever you go to get the medication, they tell you to go back to Dantec." Obtaining morphine is further complicated by the strict regulations that the government enacted due to fears of opiate misuse. By law, doctors can only prescribe a week's supply of morphine at a time. Consequently, Bineta's family would have to make the three-hour trip to Dakar each week to get the medication, which they could not afford to do.

At home, Bineta continued to suffer from pain for three months. In December 2012, she and her mother made the journey back to Dantec Hospital, because Bineta's pain had, according to her mother, become "incredibly severe." When they arrived in Dakar however, they found that there was a morphine shortage, a frequent problem in Senegal. There was no oral morphine left in the country, and pharmacists estimated that new stock would not arrive until early 2013.

Because Bineta never finished her post-operative chemotherapy, she had relapsed and was in a severe condition. Doctors at Dantec scheduled her for another surgery in March 2013. Bineta's health, however, rapidly deteriorated. She passed away on March 1, 2013, in her home, without any form of medical support. After months of severe pain that was never alleviated, Bineta died in excruciating circumstances.



Every year, there are thousands of children and adults in Senegal who face a similar fate as Bineta's. Non-communicable diseases, such as cancer, diabetes and heart disease, are responsible for 30 percent of all deaths in Senegal, and cancer alone kills more Senegalese than malaria, tuberculosis, and HIV/AIDS combined. Moreover, the prevalence of non-communicable illnesses in Senegal, as in Africa as a whole, is projected to increase significantly in the coming decades, due to life-style changes and population aging.

(above) Podor Health Center serves approximately 24,000 people but has no morphine. For palliative care, patients must travel 10 hours to Dakar.

Yet, Senegal's health system has traditionally focused primarily on acute health problems, with limited funds dedicated to chronic and non-communicable illness. Diagnosis is often made late, treatment options are limited, and medical care is costly. A large percentage of patients with chronic, life-threatening illnesses develop pain and other debilitating symptoms. Research shows that as many as 80 percent of patients with advanced cancer, and about 50 percent of those with AIDS, develop moderate to severe pain. The difficulties in providing curative care make palliative care and pain relief especially critical.

Palliative care, a health service that focuses on alleviating suffering, can be offered at relatively low cost and at all levels of the healthcare system, including in rural communities; Uganda and Rwanda for example, have implemented palliative home care services with morphine syrup and rotating nurses in rural areas. Patients like Bineta could have their symptoms treated effectively with inexpensive medications and basic training. The World Health Organization (WHO) defines morphine as an "essential" medicine for treating pain. It is cheap, highly effective, and generally not complicated to administer. In addition to pain treatment, palliative care also addresses other symptoms, both physical, like vomiting and nausea, or psychosocial, like anxiety and depression.



Dr. Abdul Kasse, oncologist, holds a packet of oral opiate pills in Dakar, Senegal on July 4, 2013. Senegalese doctors struggle to obtain these medications.

WHO has emphasized that palliative care is an integral and essential part of comprehensive care for cancer, HIV, and other conditions. Palliative care, which should be administered from the time of diagnosis, is an important support for curative care, and the only medical relief available to the terminally ill. With respect to cancer, for example, WHO has noted that:

The majority of cancer patients will need palliative care sooner or later. In developing countries, the proportion requiring palliative care is at least 80 percent. Worldwide, most cancers are diagnosed when already advanced and incurable... [For these patients] the only realistic treatment option is pain relief and palliative care.

Similarly, at the African Union (AU) Heads of State Summit in May 2013, the AU recognized the rapid rise of non-communicable disease in the region and adopted the African Common Position on Controlled Substances and Access to Pain Management Drugs (decision number EX.CL/Dec743(XXII)). This document urges member states to take the necessary steps to ensure the availability of pain treatment. During that same month, health ministers from around world, including Senegal, unanimously approved the WHO Global Action Plan for the Prevention and Control of Non-Communicable Diseases for 2013–2020, which calls upon states to “develop and implement a palliative care policy using cost-effective treatment modalities, including opioids analgesics for pain relief and training health workers.”

Despite these global developments, availability of palliative care in Senegal is almost non-existent; the World Palliative Care Association classified Senegal, and more than half of the countries in Francophone Africa, as having “no



A shipment of oral morphine pills arrived at Dakar’s Dantec Hospital in July 2013, after a shortage.

known palliative care activity.” Based on the WHO system of estimation, approximately 70,000 people with life-limiting illnesses require palliative care each year in Senegal. Research by Human Rights Watch in Senegal, conducted in 2012 and 2013, suggests that only a tiny fraction of patients actually have access to it. The most recent records indicate that Senegal uses an annual amount of morphine that is only sufficient to treat only about 194 patients suffering from pain due to advanced cancer. At time of writing, Senegal does not have any designated palliative care services, and outside Dakar, palliative care is altogether unavailable. On visits to Dantec Hospital’s Joliot Curie Institute in Dakar, the only cancer ward in the country, we saw numerous patients with advanced diseases writhing, trembling, and moaning from pain while in their hospital beds.

The vast majority of the Senegalese patients who require palliative care spend their last weeks or months in their homes, where they return when all treatment options have been exhausted or when money to pay for treatment runs out. While many of these patients can count on strong family support as their illness progresses, they often face symptoms that can only be adequately addressed with help from healthcare workers and medication, which is largely unavailable. As a result, these patients and their families end up abandoned by the healthcare system at arguably the most vulnerable time of their lives, and face tremendous suffering that could be prevented with basic palliative care.



Morphine powder is used to create morphine syrup, which the World Health Organization has designated an essential medicine. There is only one company that imports the powder in Senegal and shortages are common.

POLICY, EDUCATION AND DRUG AVAILABILITY

The World Health Organization has urged countries to take action in policy making, education, and drug availability. While there is some overlap between these three areas, WHO has identified each of them as fundamental to the development of palliative care services. Measures to address these areas cost little, but can have a significantly positive impact on improving access to care.

Policy: The WHO has recommended that countries establish a national palliative care policy or program, and that palliative care services are made available at the community level and in specialized hospitals for low- and middle-income

countries. Such programs should include provisions for improving adult and pediatric care. In Senegal however, palliative care is highly centralized, with limited services available only in Dakar; there is virtually no support for home care or community level hospices. As of 2011, WHO reports that Senegal has no national strategy for cardiovascular disease, respiratory disease, diabetes, or cancer. There is no cancer registry or information gathering on non-communicable disease. Senegal has an HIV plan for 2007-2011, but it does not include palliative care. Not only is there a problem of inaction, there are also several regulatory and legal barriers that actively inhibit palliative care development. Such barriers limit access to medications (see “drug availability” below). The government has not adopted a palliative care policy, or otherwise articulated a vision for how services can be made available to patients and existing barriers remedied.

Education: WHO also recommends that countries ensure adequate instruction of healthcare workers on palliative care and pain management. Yet, in Senegal, official medical and



(above) Dantec Hospital goes through a complicated process to obtain morphine powder, which the pharmacy mixes with water and sugar to make morphine syrup.

(right) Prepared morphine syrup at Dantec Pharmacy; one week's supply costs around US\$1.



nursing school curricula have not kept pace with the epidemiological developments that have led to rapidly increasing need for palliative care services. Medical schools do not have courses on palliative care, and while pain management is taught as a component of physiology and anesthesiology, there are no stand-alone classes on the subject. There is no specialization on palliative care, and very few, if any, post professional training sessions on managing chronic pain. Most nursing schools also do not have courses on palliative care, rather students receive two to four hours of palliative care training as part of their general “nursing care” class. As a result, many medical doctors and nurses in Senegal are unfamiliar with basic tenets of palliative care and may retain

antiquated or erroneous perceptions of opiate analgesics, such as the belief that opiates are drugs of last resort and only appropriate for the imminently dying.

Drug Availability: WHO recommends that countries establish a rational drug policy that ensures accessibility of essential medicines, including opioids like morphine. In the context of the international war on drugs, many countries have focused primarily on the potential risks of opiates, while neglecting the obligation to ensure they are available for medical purposes. The International Narcotics Control Board, a United Nations body, found in 2010 that Senegal’s consumption of opioid analgesics was at such a low level that palliative care was almost impossible, an assessment that Human Rights Watch’s research confirms.



A nurse changes bandages for a cancer patient who does not have morphine for her pain.

PROCUREMENT, DISTRIBUTION, AND PRESCRIPTION

Procurement: Healthcare facilities commonly endure morphine shortages caused by difficulties in the procurement process. Senegal's National Pharmacy (Pharmacie National d'Approvisionnement, PNA) is a centralized government agency that procures and distributes all items on Senegal's "list of essential medicines." Injectable morphine was on the 2008 list, but oral morphine, the formulation recommended by WHO for chronic pain, was not. At time of writing, the government made an important improvement by adding oral morphine tablets and tramadol, a weak opioid medication for moderate pain, to the 2012 list, which would take effect in 2013.

However, it did not add morphine syrup, a liquid formulation which is necessary for pediatric palliative care and patients with throat tumors or those who cannot swallow solid medications. To obtain drugs that are not on the list, public institutions, like hospitals must undertake a convoluted bidding process. If no seller responds to the call for bids, the hospital has no supplier, and patients will not have the medication. Three hospitals in Dakar have launched bidding calls for oral morphine tablets with no success, not only because the profit margin on the medication is slim, but also because bidding is limited to domestic companies. Creating flexibility to allow hospitals to make direct purchases of medication from national and international sources will help them stock their pharmacies adequately and consistently.

Distribution: Incurably ill patients have to travel, often long distances, for medications that should be available at all levels of the healthcare system. The 2012 list explicitly limits morphine to regional and national hospitals, which means they will only be available in the main cities. Many Senegalese



A six-year-old boy with liver cancer in the waiting room at Dantec Hospital Pediatric Oncology Ward, the only facility in Senegal that provides pediatric cancer care. His family lives far away, so he must stay with his uncle in Dakar.

live several hours away from the nearest hospital and rely exclusively on health centers or health posts, neither of which are currently authorized to stock opiates. Additionally, even though regional hospitals are allowed to stock opiates, none of the Regional Pharmacies (Pharmacie Régionale d'Approvisionnement, PRA), the regional branches of the PNA, stocked it. Human Rights Watch visited several regional hospitals, and in all of them, various healthcare providers said they wanted to use morphine, but the hospital pharmacist or their PRA told them it was unavailable. Meanwhile, officials at the PNA told Human Rights Watch that they consult with regional healthcare facilities on their need for opiates, and none of them order morphine. Regional doctors do not use morphine because it is unavailable, and

the PRAs do not stock it because no one uses it. The government must organize a dialogue to end this cycle, and ensure that not only is morphine available in all regions, but that regional healthcare workers are aware of its availability.

Prescription: Only doctors can prescribe morphine, and only with a specialized prescription pad, which severely limits access to opiate medication outside Dakar, where there is doctor to patient ratio is extremely low, one doctor for every 11,000 individuals. Nurses in Senegal are authorized to prescribe almost all medications, but not morphine and strong opioids. Other countries with similar dynamics have altered regulations to allow nurses, or even community healthcare workers, to prescribe oral opiates. Even for doctors, Senegal's drug law imposes a one-week limit for prescriptions of opioid analgesics. As a result, patients or their relatives must visit the pharmacy every week for a new prescription. Given the limited facilities that stock morphine, most people, especially the terminally ill and those who live outside of Dakar, cannot travel so often. While the law allows the Ministry of Health to significantly extend the one-week



A four-year-old boy with bone cancer arrived at Dantec during a morphine shortage in severe pain, after six months of misdiagnosis in other facilities. He passed away two weeks after this photo was taken.



period by ministerial decree, the Ministry has not done so. With this one-week limit, Senegal is becoming an outlier as many countries have increased prescription limits, generally to a month or more.

Senegal has a human rights obligation to promote access to healthcare, and Senegal's commitment to the right to health is explicitly guaranteed in the Senegalese Constitution, and affirmed by Senegal's membership in numerous human rights conventions, including the International Covenant on Economic, Social and Cultural Rights (ICESCR), African Charter on Human and Peoples' Rights (ACHPR), and the Convention on the Rights of the Child (CRC). Under the ICESCR, Senegal is obligated to take steps "to the maximum of its available resources" to progressively achieve the rights in the Covenant, including access to health and palliative care. Article 16 of the African Charter on Human and Peoples' Rights states that, "every individual shall have the right to enjoy the best attainable state of physical and mental health...State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick." The CRC's article 24 states, "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health...States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services."

Additionally, the international prohibition of torture and ill-treatment dictates that governments have a positive obligation to protect people from unnecessary suffering and extreme pain. The UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has noted that, "failure of governments to take reasonable measures to ensure accessibility of pain treatment...raises questions whether they have adequately discharged this obligation." The Senegalese government must refrain from directly violating human rights, but fulfilling its obligations also entails taking active measures to make the right to health a reality.

Senegal has several obstacles to overcome, but it has healthcare workers and experts who are dedicated to making positive changes, and an existing infrastructure that can facilitate decentralization. A palliative care strategy for Senegal should focus on providing access to services in or near patients' communities, which can be done by organizing health care training in basic symptom management and by ensuring wide access to medications. Utilizing rotating nurses equipped with a vehicle and oral morphine, similar to Senegal's current system for malaria treatment and vaccination in rural areas, can greatly expand access in a cost effective manner. A palliative care strategy should also address the special needs of children with life-limiting illness,



Adama, a 14-year-old girl with Leukemia, traveled over an hour each week for treatment at Dantec Hospital, where she got morphine syrup to relieve her pain. Adama passed away in June 2013.

by providing a plan to implement palliative care in pediatrics, train pediatricians and pediatric nursing staff to assess and treat symptoms in children, and ensure the availability of child-friendly formulations of key medications, such as morphine syrup.

To make progress in this area, the government can draw on its own experiences with the decentralization of and financial support for services for HIV/AIDS, malaria and tuberculosis, as well as on experiences from other African countries that have decentralized palliative care, like Rwanda and Uganda. Several other African countries have organized meetings with all relevant parties—health authorities, drug regulators,

pharmaceutical suppliers, palliative care experts, and others—to develop and implement a comprehensive palliative care strategy. The Senegalese government should collaborate with the Association Sénégalaise de Soins Palliatifs (ASSOPA), a coalition of healthcare workers dedicated to promoting palliative care in Senegal, to organize such a meeting.

Specifically, the government needs to arrive at a more accurate estimate of its annual quota for morphine by referring to the INCB guidelines. Since currently no morphine is used in most regions, an estimation of need cannot be based on current use—rather, it must take into account the actual number of people living with pain, from NCDs, chronic illness, or other diseases. To prevent shortages and increase affordability, the government must ensure that the National Pharmacy takes charge of importing all essential palliative care medications, including oral morphine in liquid and pill



Brain lesions cause two-year-old Alpha Balde's eyes to bulge out from his skull. His form of cancer (acute lymphoblastic leukemia) has a survival rate of over 90 percent in the United States, but the treatment he needs is unavailable in Senegal.

form. Importation must be consistent and based on accurate evaluation of the needs of the population. The National Pharmacy must distribute these medications to the Regional Pharmacies, and regional health facilities, including those at the district and community level, should be authorized to stock them. Expanding authority to prescribe opiates to nurses is critical for rural areas.

Combating non-communicable diseases will necessitate improvements in prevention, curative treatment, and palliative care. Palliative care is easy and cheap to implement; it can be done quickly, and has an enormous impact on the

well being of patients, families, and healthcare workers. It supports those who can be cured by addressing agonizing symptoms, and is the only comfort for those who are terminal. Though palliative care would not have saved Bineta's life, it would have relieved her suffering considerably. When the majority of Senegalese with non-communicable diseases reach advanced stages of illness where pain is severe and a cure is elusive, ignoring palliative care is illogical. While the government continues to expand access to prevention and curative treatment, the development of palliative care services is necessary to minimize anguish and pain. The right to health is a progressive process, and it begins with concrete steps. No patient should be allowed to suffer when modern medicine can easily prevent it.

KEY RECOMMENDATIONS

The Senegalese government should, in consultation with health care providers, international donors, WHO, non-governmental organizations, and other stakeholders, urgently develop action plans to ensure access to palliative care and pain management nationwide. In particular, they should:

- **Develop national palliative care policies and strategies, as recommended in the WHO Global Action Plan on Non-Communicable Diseases, and identify specific benchmarks and timelines for implementation. These should provide for both the establishment of palliative care services at tertiary hospitals as well as integrate palliative care into the services provided at all levels of the health care system and in the community. National palliative care policies and strategies should also include considerations for children’s palliative care.**
- **Develop national cancer and non-communicable programs for adults and children, and integrate meaningful palliative care strategies within these programs. Integrate palliative care into the national HIV/AIDS plan and services.**
- **Review the law on drugs, relevant regulations, and implementing practice to ensure that they do not unnecessarily impede access to strong opioid analgesics. In particular, the ministry of health should significantly extend the one-week limitation on prescriptions for strong opioids. Refer to the WHO Guidelines on Ensuring Balance in National Policies on Controlled Substances.**
- **Ensure that all palliative care medications on the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children are included in Senegal’s essential medicines list, including morphine syrup or, alternatively, morphine powder.**
- **Undertake an accurate and comprehensive assessment of need for morphine in the country and, accordingly, request a higher morphine quota from the INCB. Refer to the INCB’s Guide on Estimating Requirements for Substances under International Control.**
- **Ensure that the PNA, the national pharmacy, consistently procures enough essential palliative care medications, including strong opioid analgesics, and distributes opioid analgesics to the PRAs, their regional affiliates. In turn, ensure that the PRA supplies opioid analgesics to all relevant public healthcare facilities.**
- **Allow the PNA, hospitals, and other public facilities involved in the purchase of medications the flexibility to make direct orders of medications from national and international vendors.**
- **Develop and implement a program of continuing medical and nursing education on palliative care for existing health care workers, including those working in the communities. In particular, give basic training on giving dosage of and administering oral opioid analgesics.**
- **Mandate the inclusion of basic instruction on palliative care, for adults and children, in the curriculum of all medical and nursing colleges, and develop opportunities to pursue in depth specialization on palliative care.**
- **Implement the WHO Global Action Plan on Non-Communicable Diseases and take steps to improve diagnosis and curative treatment for chronic and life limiting illnesses for adults and children. Develop funding strategies to better ensure access to treatment for impoverished patients.**

Methodology

Field research for this report was carried out in November and December 2012 and July 2013 in Senegal. Interviews were conducted at 10 different health facilities in Dakar, Podor and Ndoum (St. Louis Region), Ziguinchor (Ziguinchor Region) and Thiès (Thiès Region). We chose to visit Podor and Ziguinchor because we took the decision to investigate the availability of palliative care in rural areas. For various reasons, including the limited number of Human Rights Watch researchers working on the project, we could not visit all 14 regions in Senegal. As such, we chose one Northern district (Podor) and one Southern district (Ziguinchor). We visited Thiès because it is the closest major city to the capital. Over the course of five weeks in Senegal, Human Rights Watch researchers conducted 160 interviews with a wide variety of stakeholders, including 41 adult patients, 41 relatives of pediatric patients, and 61 healthcare workers, including oncologists, pharmacists, and nurses, and 8 health officials. We also interviewed government officials, representatives of pharmaceutical companies and nongovernmental and international organizations.

We conducted most interviews with patients and their families at healthcare institutions such as hospitals and health clinics. Healthcare workers at these facilities helped us identify patients with incurable illnesses for in-depth interviews. Though palliative care is necessary in a variety of health fields, this report focused on cancer patients because cancer is an increasing problem in Senegal, and since cancer care is not decentralized, Dakar hospitals have large numbers of cancer patients from various parts of the country. Where possible, interviews were conducted in private. Due to their illness, some patients were immobile and shared a room. In such cases, we made sure the patient was comfortable conducting the interview under those circumstances. If not, no interview was done. Interviews were semi-structured and covered a range of topics related to curative and palliative treatment.

Before each interview, Human Rights Watch informed interviewees of its purpose, the kinds of issues that would be covered, and asked if they wanted to participate. We informed them that they could discontinue the interview at any time or decline to answer any specific question, without consequence—we took particular care to emphasize this point to patients who appeared to be in serious condition. No incentives were offered or provided to persons interviewed. We told patients that we could not provide medication,

but in situations where people were in acute need of pain relief or other medical care, we brought their condition to the attention of a nurse or doctor. We have disguised the identities of all patients we interviewed in this report to protect their privacy. The identities of some other interviewees, including government officials, have also been withheld at their request.

We conducted approximately half the interviews with patients and their relatives in the pediatric oncology ward at Dantec Hospital in Dakar. In total, we interviewed the parents or guardians of 41 children there. We interviewed two teenage children directly, in the presence of a parent. Most of the children concerned had confirmed diagnoses of cancer. In many cases however, family members were not able to precisely identify what the child's illness was, either because no diagnosis had been made, the diagnosis had not been communicated to the family, or the family had not understood the diagnosis.

Human Rights Watch conducted 41 interviews with adult patients, many who had family members present. Four of those interviews were conducted solely with family members because the patients were unable to speak. All patient interviews were done in Dakar, with the exception of one such interview in Thiès. We avoided patient interviews outside of Dakar for ethical reasons—no palliative care or pain management is available outside the capital and we did not want to ask patients to articulate the impact of pain or other symptoms on their lives when there was no possibility of referring them to appropriate care. The patient interviewed in Thiès was not suffering from severe pain or other symptoms.

We interviewed 61 health professionals in five cities, including 32 doctors, 16 nurses, 9 pharmacists, 2 health volunteers, and 2 midwives. These interviews concerned barriers to pain treatment and palliative care generally, but we also asked them to discuss cases of patients who suffered because palliative care was not available. We also sought their opinion on measures that could be taken to improve access to palliative care in Senegal.

We also interviewed representatives of the Ministry of Health, Ministry of Pharmacies and Medicines (Direction des Pharmacies et des Médicaments), National Pharmacy (Pharmacie Nationale D'Approvisionnement), and the Regulatory Authority on Public Markets (Autorité de Régulation des Marchés Publics).

Interviews with health care workers and officials were conducted in French. Interviews with patients and their families were carried out in French, Wolof and Pular. An experienced interpreter, multi-lingual healthcare workers, or multi-lingual family members provided translation when necessary. The interpreter was briefed extensively on the topic of the interviews and on the sensitive nature of working with people with life-limiting conditions. The interpreter was also briefed on Human Rights Watch's confidentiality policies.

I. Background

The Global Burden of Non-Communicable and Chronic Illnesses

Non-communicable diseases (NCDs), such as cancer, heart disease, diabetes, and respiratory illnesses, are by far the leading cause of mortality in the world, causing 63.5 percent of all deaths.¹ Chronic illness, including HIV/AIDS and many NCDs, typically leave patients in need of continued medical support. More than 80 percent of adults over 60 years of age have at least one chronic disease.² With life expectancy increasing worldwide, the number of people aged 60 and over is expected to more than triple by the end of this century, meaning that the prevalence of these diseases will rise dramatically.³

Current projections indicate that by 2020, the largest increases in deaths from non-communicable diseases will occur in Africa.⁴ According to the United Nations, 3.7 million NCD deaths were recorded in sub-Saharan Africa in 2008, but that number will balloon to 14 million by 2050.⁵ In 2007, there were over 700,000 new cancer cases and nearly 600,000 cancer-related deaths in Africa,⁶ and cancer rates in the region are estimated to grow by 400 percent in the next five decades.⁷ Cardiovascular disease is on the rise, and it is already the leading cause of death of Africans over 45-years-old.⁸ Africa already has the

¹ 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, <http://www.un.org/esa/population/publications/levelsandtrends/mortality/Changing%20levels%20and%20trends%20in%20mortality.pdf> (accessed July 10, 2013), p. 7.

² Grace Christ and Sadhna Diwan, "Chronic Illness and Aging: The Demographics of Aging and Chronic Diseases," Council on Social Work and Education, undated, <http://www.cswe.org/File.aspx?id=25462> (accessed August 5, 2013), p. 7.

³ UNDESA Population Division, "World Population Prospects: The 2012 Revision," 2013, http://esa.un.org/wpp/Documentation/pdf/WPP2012_%20KEY%20FINDINGS.pdf (accessed July 10, 2013), p. 4. "Globally, the number of persons aged 60 or over is expected to more than triple by 2100, increasing from 841 million in 2013 to 2 billion in 2050 and close to 3 billion in 2100. Furthermore, already 66 per cent of the world's older persons live in the less developed regions and by 2050, 79 per cent will do so. By 2100, this figure will reach 85 per cent."

⁴ World Health Organization (WHO), "Noncommunicable Diseases," March 2013, <http://www.who.int/mediacentre/factsheets/fs355/en/> (accessed June 11, 2013).

⁵ UNDESA, "Population Ageing and Non-Communicable Diseases," April 2012, http://www.un.org/en/development/desa/population/publications/pdf/popfacts/popfacts_2012-1.1.pdf (accessed July 11, 2013), p. 2.

⁶ American Cancer Society, "Cancer in Africa, Atlanta: American Cancer Society, 2011, www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-031574.pdf (accessed April 25, 2013), citing Jacques Ferlay, Hai-Rim Shin, Freddie Bray, David Forman, Colin Mathers, Donald Maxwell Parkins, *Cancer Incidence and Mortality Worldwide: IARC Cancer Case No. 10*, Lyon, France: International Agency for Research on Cancer, 2010.

⁷ African Association for Palliative Care, "Regional Report: Africa," February 2008, www.hospicecare.com/new/08/02/regional.html (accessed July 10, 2013).

⁸ Thomas A. Gaziano, "Growing Epidemic of Coronary Heart Disease in Low- and Middle-Income Countries," National Center for Biotechnology Information, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2864143/> (accessed July 10, 2013).

world's highest age standardized mortality rate for diabetes,⁹ and the prevalence of diabetes is predicted to increase by 80 percent in the next 20 years.¹⁰ By 2030, non-communicable illnesses are likely to surpass maternal, child and infectious diseases as the biggest killer in the region.¹¹

One of the challenges sub-Saharan African countries face in combating chronic diseases is the fact that their healthcare systems are often designed to respond to acute health problems, such as infectious disease and injuries.¹² HIV/AIDS remains an enormous problem in Africa, with an estimated 23.5 million Africans living with HIV/AIDS, and 1.8 million new infections in 2011,¹³ but it is necessary to acknowledge the rapid rise, and growing death toll of NCDs. Foreign aid, which accounts for significant proportions of health budgets in many sub-Saharan countries, predominantly goes to infectious diseases and maternal and child health.¹⁴ Less than 3 percent of this aid goes to NCDs.¹⁵

As a result, non-communicable diseases kill far more people, and far earlier, in poor countries than in rich ones. Ninety percent of premature deaths (those before 60 years of age) from NCDs occurred in low- and middle-income countries,¹⁶ and Africa has the

⁹ Pfizer, "The Global Burden of Non-Communicable Diseases," September 2011, <http://www.pfizer.pt/Files/Billeder/Pfizer%20P%C3%ABalico/Not%C3%ADcias/Global%20Burden%20of%20Noncommunicable%20Diseases.pdf> (accessed July 10, 2013), p. 4.

¹⁰ Michelle D. Holmes et. al, "Non-Communicable Diseases in Sub-Saharan Africa: the Case for Cohort Studies," May 11, 2010, <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000244#pmed.1000244-Parkin1> (accessed June 11, 2013).

¹¹ "Growing Pains: Poor Countries are Developing the Diseases of the Rich, with Lethal Consequences," *The Economist*, September 24, 2011, <http://www.economist.com/node/21530099> (accessed June 11, 2013). See also, WHO, "Noncommunicable Diseases," <http://www.who.int/mediacentre/factsheets/fs355/en/> (accessed August 5, 2013).

¹² "Growing Pains: Poor Countries are Developing the Diseases of the Rich, with Lethal Consequences," September 24, 2011, *The Economist*, <http://www.economist.com/node/21530099> (accessed June 11, 2013).

¹³ UNAIDS, Sub-Saharan Africa Regional Factsheet 2012, November 20, 2012, http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/2012_FS_regional_ssa_en.pdf (accessed July 11, 2013).

¹⁴ Dambisa Moyo, "Why Foreign Aid is Hurting Africa," *The Wall Street Journal*, March 21, 2009, <http://online.wsj.com/article/SB123758895999200083.html> (accessed June 11, 2013); Foreign aid comprised 50% of the budgets of Ghana and Uganda in 2005; Tolu Ogunlesi, "Wanted Dead or Alive: Foreign Aid in Africa," *Good Governance Africa*, <http://gga.org/analysis/wanted-dead-or-alive-foreign-aid-in-africa> (accessed June 11, 2013); Foreign aid comprises 40% of Malawi's government budget. "Senegal," Index of Economic Freedom, 2013, <http://www.heritage.org/index/country/senegal> (accessed June 11, 2013); In Senegal, foreign assistance comprised over 20 percent of government spending in 2007.

¹⁵ Rachel Nugent and Andrea Feigl, "Where Have All the Donors Gone? Scarce Donor Funding for Non-Communicable Diseases Working Paper," November 1, 2010, <http://www.cgdev.org/publication/where-have-all-donors-gone-scarce-donor-funding-non-communicable-diseases-working-paper> (accessed July 11, 2013).

¹⁶ WHO, "Noncommunicable Diseases," <http://www.who.int/mediacentre/factsheets/fs355/en/> (accessed August 5, 2013).

highest age standardized mortality for NCDs in the world.¹⁷ The impact is especially significant in children; the Union for International Cancer Control estimates that as few as 5 percent of childhood cancer cases in Africa are cured, compared with nearly 80 percent in the developed world.¹⁸

Global Palliative Care Needs and Regional Availability

Non-communicable and other chronic diseases are often accompanied by pain and other distressing symptoms. Approximately 80 percent of patients with advanced cancer, 50 percent of individuals with advanced HIV,¹⁹ and 60 to 70 percent of people with diabetes suffer from moderate to severe pain during the course of their illness.²⁰ While pain management is also necessary for a wide variety of medical fields, including acute trauma and post-operative care, the rapid growth of NCDs and chronic illness creates an increased need for long term pain and symptom management strategies.²¹ Though NCDs and chronic illnesses may ultimately cause death, many patients will live with these diseases for several years.²² The Global Burden of Disease study of 2010 accounts for the impact of ill health on quality of life by using the term “disability-adjusted life years,” which measures years of life lost due to ill-health, disability, and early death.²³

¹⁷ Pfizer, “The Global Burden of Non-Communicable Diseases,”

<http://www.pfizer.pt/Files/Billeder/Pfizer%20P%C3%ABlico/Not%C3%ADcias/Global%20Burden%20of%20Noncommunicable%20Diseases.pdf>, p. 4 (accessed August 5, 2013).

¹⁸ International Union Against Cancer (UICC), “Cancer Control in Africa: Declaration Presented during the Cancer Control in Africa Meeting London, UK, May 10-11, 2007,”

http://www.uicc.org/index.php?option=com_content&task=view&id=15726&Itemid=631 (accessed February 12, 2013).

“Cure” is understood to mean 5-year survival after remission. International Agency for Research on Cancer (IARC), WHO, “Cancer in Africa, Epidemiology and Prevention,” 2003, <http://www.iarc.fr/en/publications/pdfs-online/epi/sp153/SP153.pdf> (accessed March 18, 2010). There are few reliable statistics on cancer in Africa, due to the absence of cancer registries, and no reliable estimates for the number of child deaths from cancer; see also David J. Kerr, “London Conference Examines Growing Cancer Burden in Africa,” American Society of Clinical Oncology (October 2007), <http://www.asconews.org/anf/Past+Issues/October+2007/London+Conference+Examines+Growing+Cancer+Burden+in+Africa?cpsexcurrchannel=1> (accessed April 15, 2013).

¹⁹ Kathleen M. Foley, Judith L. Wagner, David E. Joranson, and Hellen Gelband, “Pain Control for People with Cancer and AIDS”, in *Disease Control Priorities in Developing Countries*, eds. Dean T. Jamison, Joel G. Breman, Anthony R. Measham, et al. (New York: Oxford University Press, 2006) p.981–993.

²⁰ Sarah Krein et. al., “The Effect of Chronic Pain on Diabetes Patients’ Self-Management,” *Diabetes Care*, vol. 28, Number 1, (January 2005) <http://care.diabetesjournals.org/content/28/1/65.full.pdf+html> (accessed January 29, 2013). See also, National Diabetes Information Clearing House, “Diabetic Neuropathies: The Nerve Damage of Diabetes,” June 25, 2012, <http://diabetes.niddk.nih.gov/dm/pubs/neuropathies/> (accessed January 29, 2013).

²¹ Christopher Murray et. al., “Disability-Adjusted Life Years (DALYs) for 291 Diseases and Injuries in 21 Regions, 1990–2010: A Systematic Analysis for the Global Burden of Disease Study 2010,” *The Lancet*, Vol. 380, Issue 9859, (December 15, 2012) [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)61689-4/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61689-4/abstract) (accessed August 5, 2013).

²² Ibid.

²³ Ibid.

Pain has a profound impact on quality of life for both adult and pediatric patients. Debilitating symptoms can lead to reduced mobility and consequent loss of strength, compromise the immune system, and interfere with a person's ability to eat, concentrate, sleep, or interact with others. More generally, people with chronic illness are also more likely to suffer from depression or anxiety, and many individuals lose the will to live and may even become suicidal.²⁴ The physical effect of chronic pain and the psychological strain it causes can influence the course of a disease, and severe pain can actually lead to death.²⁵ For families and caregivers, watching a person suffer from symptoms and medical procedures and facing the prospect of potential death can cause great distress.

Palliative care is designed to address these concerns and to improve patients' quality of life through pain and symptom relief, and psychosocial support for patients and their families.²⁶ Despite a common misconception, palliative care is not limited to end-of-life care and does not mean "giving up" on the patient.²⁷ Indeed, it corresponds to perhaps the most fundamental duty of healthcare providers: to alleviate suffering. Though pain is a central issue, palliative care also addresses various other symptoms, such as vomiting, nausea, fever, urinary problems and bowel complications.

According to WHO, "Most, if not all, pain due to cancer *could* be relieved if we implemented *existing* medical knowledge and treatments." (emphasis added)²⁸ The standard tool for treating cancer pain is WHO's Pain Ladder, which is a three-step approach of administering the right drug in the right dose at the right time.²⁹ The ladder recommends the use of increasingly potent pain killers as pain becomes more severe, from basic pain medicines (such as acetaminophen, aspirin, or ibuprofen), to weak opioids like codeine, to strong opioids like morphine. For pediatrics, WHO recommends a two-step approach, skipping weak opioids and moving directly from low level analgesics to strong opioids.

²⁴ Oye Gureje, et al., "Persistent Pain and Well-being: A World Health Organization Study in Primary Care," *Journal of the American Medical Association*, vol. 280 (1998), pp. 147-151.

²⁵ Justin Amery, *Children's Palliative Care in Africa*, (London: Oxford University Press, 2009), p. 98.

²⁶ WHO, "Palliative Care," undated, <http://www.who.int/cancer/palliative/en/> (accessed July 31, 2013).

²⁷ Eric Krakauer, "Just Palliative Care: Responding Responsibly to the Suffering of the Poor," *Journal of Pain and Symptom Management*, vol. 35, no. 5 (November 2008), p. 506.

²⁸ WHO, "Achieving Balance in Opioid Control Policy: Guidelines for Assessment," 2000, <http://www.medsch.wisc.edu/painpolicy/publicat/oowhoabi/oowhoabi.pdf> (accessed August 5, 2013), p. 1.

²⁹ WHO, "WHO's Pain Ladder," undated, <http://www.who.int/cancer/palliative/painladder/en/index.html> (accessed January 29, 2013).

The mainstay medication for the treatment of moderate to severe pain is morphine, an inexpensive opioid that is made of an extract of the poppy plant. Morphine can be injected and taken orally, in tablet or liquid form. Injectable morphine is usually used to treat acute pain, generally in hospital settings. Oral morphine is the drug of choice for chronic pain, and can be taken both in institutional settings and at home. Morphine is a controlled medication, meaning that its manufacture, distribution, and dispensation are strictly regulated both at the international and national levels.

Medical experts have recognized the importance of opioid pain relievers for decades. The 1961 Single Convention on Narcotic Drugs, the international treaty that governs the use of narcotic drugs, explicitly states that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering” and that “adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”³⁰ The World Health Organization has included both morphine and codeine in its Model List of Essential Medicines and its Model List of Essential Medicines for children, which should be available to all persons who need them.³¹

Yet, approximately 80 percent of the world population has either no or insufficient access to treatment for moderate to severe pain, and tens of millions of people around the world, including around 5.5 million cancer patients and one million end-stage HIV/AIDS patients, suffer from moderate to severe pain each year without treatment.³²

In many African countries, palliative care is neglected by policy makers and health providers. According to the Worldwide Palliative Care Alliance (WPCA), half of sub-Saharan Africa’s countries have no known palliative care services.³³ Only six sub-Saharan African

³⁰ Single Convention on Narcotic Drugs, adopted March 30, 1961, United Nations Economic and Social Council (ECOSOC) 689 J (XXVI), as amended by the 1972 Protocol amending the Single Convention on Narcotic Drugs, 1961, preamble, http://www.unodc.org/pdf/convention_1961_en.pdf (accessed July 11, 2013).

³¹ WHO, “Model List of Essential Medicines,” April 2013, http://www.who.int/medicines/publications/essentialmedicines/18th_EML_Final_web_8Jul13.pdf (accessed July 11, 2013), and WHO, “Model List of Essential Medicines for Children,” April 2013, http://www.who.int/medicines/publications/essentialmedicines/4th_EMLc_FINAL_web_8Jul13.pdf (accessed July 11, 2013).

³² WHO Briefing Note, “Access to Controlled Medications Programme,” February 2009, http://www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrL_EN_Feb09.pdf (accessed July 17, 2009).

³³ Worldwide Palliative Care Alliance, “Mapping Levels of Palliative Care: A global Update,” 2011 <http://www.thewpca.org/latest-news/mapping-report-2011/> (accessed August 5, 2013); Out of 37 sub-Saharan African countries, Benin, Burkina Faso, Burundi, Cape Verde, Central African Republic, Chad, Djibouti, Equatorial Guinea, Eritrea, Gabon, Guinea, Guinea-Bissau, Liberia, Mauritania, Niger, Senegal, Somalia, Togo, Sahara are categorized as having no known palliative care activity—a total of 18.

countries—Kenya, Rwanda, South Africa, Swaziland, Tanzania, and Uganda—have integrated palliative care into their national health plans.³⁴ Only four countries—Kenya, Malawi, South Africa, and Uganda—recognize palliative care as an examinable subject in medical schools and have it integrated in the curriculum of health professionals.³⁵ Palliative care seems to be particularly poor in Francophone Africa, with 11 of 18 Francophone African countries having no known palliative care services.³⁶ Most palliative care on the continent is provided by non-governmental, faith, or community-based organizations with no guaranteed sustainability.³⁷ In 2008, morphine consumption in Africa was almost 20 times lower than the global mean.³⁸

Background on Senegal

Non-Communicable and Chronic Illnesses and Palliative Care

Like other low- and middle-income countries, Senegal faces both an increasing burden of chronic illness and major challenges in responding to them. As of 2013, Senegal's population is 14.1 million,³⁹ and approximately 70,000 Senegalese need palliative care.⁴⁰ Yet, the most recent records indicate that Senegal uses an annual amount of morphine that is only sufficient to treat only about 194 patients suffering from pain due to advanced cancer.⁴¹ For 2013, Senegal estimated it would need 1,180 grams of morphine,⁴² which would be 0.084 mg per capita—71 times less than the global average of 5.96 mg per capita.⁴³

³⁴ The countries that have integrated palliative care into the healthcare plans are Kenya, South Africa, Tanzania, and Uganda. Rwanda and Swaziland have stand-alone national palliative care policies. Faith Mwangi-Powell and Olivia Dix, "Palliative Care in Africa: An overview," *Africa Health*, July 2011, http://africa-health.com/articles/july_2011/P_care_overview.pdf (accessed April 25, 2013).

³⁵ These countries are Kenya, Malawi, South Africa, and Uganda. *Ibid.*

³⁶ The 11 countries are: Benin, Burkina Faso, Burundi, Central African Republic, Chad, Djibouti, Gabon, Guinea, Niger, Senegal, Togo. Worldwide Palliative Care Alliance, "Mapping Levels of Palliative Care: A global Update," 2011 <http://www.thewpca.org/latest-news/mapping-report-2011/> (accessed August 5, 2013).

³⁷ Mwangi-Powell and Dix, "Palliative Care in Africa: An Overview," *Africa Health*, July 2011 http://africa-health.com/articles/july_2011/P_care_overview.pdf (accessed April 25, 2013).

³⁸ Average consumption in African countries was 0.33 mg per capita, compared with the global mean of 5.98 mg. *Ibid.*, citing International Narcotics Control Board, *Narcotic drugs: Estimated world requirements for 2008 – statistics for 2006*, (New York: United Nations, 2008.)

³⁹ UNDESA Population Division, "World Population Prospects: The 2012 Revision," 2013, http://esa.un.org/wpp/Documentation/pdf/WPP2012_%20KEY%20FINDINGS.pdf (accessed August 5, 2013)

⁴⁰ The WHO estimates that the number of people in a country who need palliative care is roughly equal to 0.5% of the total population; Senegal has a population of about 14 million people, which means approximately 65,000 Senegalese are in need of palliative care. See, WHO, "Cancer Control, Knowledge in Action," 2007, <http://www.who.int/cancer/media/FINAL-Palliative%20Care%20Module.pdf> (accessed June 11, 2013).

⁴¹ Kathleen M. Foley, et al., "Pain Control for People with Cancer and AIDS," estimates that the average terminal cancer or AIDS patient who suffers from severe pain will need 60 to 75mg of morphine per day for an average of about 90 days. Senegal's consumption of morphine is approximately 1 kilogram, as reported by the International Narcotics Control Board in

Relatively little reliable data is available on non-communicable diseases and chronic illness. The HIV/AIDS rate in Senegal is 0.7 percent, and there are 53,000 Senegalese living with the disease; each year, 1,600 Senegalese die from AIDS.⁴⁴ WHO estimates that NCDs account for 30 percent of all deaths in the country.⁴⁵ Of the NCD deaths in 2008, 45.1 percent, nearly half, were people under age 60.⁴⁶ According to WHO's International Agency for Research on Cancer, there are 6,600 new cases of cancer each year in Senegal, and 5,100 cancer deaths,⁴⁷ with cervical cancer and liver cancer being the most prevalent forms.⁴⁸ Based on records and estimates from UNAIDS and WHO, cancer kills more than three times the number of Senegalese as HIV/AIDS does, and also kills more Senegalese than HIV/AIDS, malaria, and tuberculosis combined.⁴⁹

In Senegal, knowledge about non-communicable diseases and cancer is limited, leading to frequent misdiagnosis and late referral of patients; as a result, a very high percentage of illnesses are diagnosed only in advanced stages.⁵⁰ A 2004 study by Dr. Ndiassé Ndiaye, an ear, nose and throat specialist at Thiès Regional Hospital, found that among 77 patients diagnosed with hypopharynx cancer, a throat cancer, 79 percent were in stage four, and 21 percent were in stage three at the time of diagnoses.⁵¹ Medical doctors interviewed for this

their technical report, available at http://www.incb.org/documents/Narcotic-Drugs/Technical-Publications/2012/NDR_2012_Part4_Tables_EFS.pdf (accessed June 11, 2013).

⁴² INCB, "Estimated World Requirements of Narcotic Drugs for 2013," 2013, http://www.incb.org/documents/Narcotic-Drugs/Technical-Publications/2012/NDR_2012_Annex_2_EFS.pdf (accessed August 6, 2013).

⁴³ In 2008, the global mean consumption of morphine was 5.98 mg; International Narcotics Control Board, *Narcotic drugs: Estimated world requirements for 2008 – statistics for 2006*, (New York: United Nations, 2008.)

⁴⁴ UNAIDS, "Senegal," 2012, <http://www.unaids.org/en/regionscountries/countries/senegal/> (accessed July 11, 2013).

⁴⁵ WHO Country Profile, "Senegal," 2011, http://www.who.int/nmh/countries/sen_en.pdf (accessed July 29, 2013)

⁴⁶ WHO, "Mortality: NCD Deaths Under Age 60 by Country," 2008, <http://apps.who.int/gho/data/node.main.A861?lang=en> (accessed July 12, 2013).

⁴⁷ As Senegal does not have a cancer registry, these figures are projections that are not based on statistics reported from the country. WHO International Agency for Research on Cancer, Globocan 2008, 2008, <http://globocan.iarc.fr/factsheet.asp> (accessed April 25, 2013).

⁴⁸ WHO International Agency for Research on Cancer, Globocan 2008, <http://globocan.iarc.fr/factsheet.asp> (accessed April 25, 2013).

⁴⁹ Oumar Ba and Aminata Coulbary, "Prise en Charge des Patients en Fin de Vie au Senegal: Soins Palliatifs et Accompagnement," Groupe Soins Palliatifs Dakar, ACPA Kampala, November 24, 2009, p. 6. See also, Radiating Hope, "Senegal," undated, <http://www.radiatinghope.org/get-involved/senegal/> (accessed June 27, 2013). According to UNAIDS, there were 1600 HIV/AIDS related deaths in Senegal in 2011, see UNAIDS, "Senegal," 2012, <http://www.unaids.org/en/regionscountries/countries/senegal/> (accessed July 11, 2013). WHO estimates that there were 2500 deaths from tuberculosis in 2011, see WHO, "Senegal Tuberculosis Profile," 2011, https://extranet.who.int/sree/Reports?op=Replet&name=/WHO_HQ_Reports/G2/PROD/EXT/TBCountryProfile&ISO2=SN&outtype=html (accessed August 5, 2013). According to WHO, there were 574 malaria related deaths in Senegal in 2009, see WHO, "World Malaria Report 2010, Annex 7A, Reported Malaria Cases and Deaths," 2010, http://www.who.int/malaria/world_malaria_report_2010/wmr2010_annex7a.pdf (accessed July 11, 2013).

⁵⁰ Human Rights Watch interview with Senegalese oncologists and HIV specialists, Dakar, November 2012.

⁵¹ Human Rights Watch interview with Ndiassé Ndiaye, ENT, Thiès Regional Hospital, Thiès, December 12, 2012.

report estimated that about 70 to 80 percent of their cancer patients arrive at their offices in late stages of illness.⁵²

Senegal's Health Care System

Senegal has a mostly public healthcare system, although some private clinics exist in Dakar. As of 2012, there are 25 hospitals, 89 health centers, 1240 health posts, and 2098 health huts in the country. There are 37 private clinics and 77 private health posts.⁵³ Of these 23 functioning hospitals, eight are in Dakar,⁵⁴ meaning about one third of the hospitals in the entire country are in Dakar. In the public system, there is approximately one doctor for every 11,000 people, and one nurse for every 4,200 people.⁵⁵

The Senegalese government spends about 12 percent of its budget on health, with an average of US\$111 per capita, which is more than most of its West African neighbors and other Francophone African states.⁵⁶ The public system consists of several different levels, with basic community-trained volunteers available at the lowest, and specialized medical care at the highest level. Depending on the nature of their health problem, patients are attended to at the lower levels of care or referred to health centers or hospitals (see Table 1).

⁵² Human Rights Watch interviews with Serigne Magueye Gueye, urologist, Grand Yoff Hospital, Dakar, November 11, 2012, and Sohkna Ndiaye, psychotherapist, Dantec Hospital Pediatric Oncology, Dakar, November 12, 2012, and Ahmadou Dem, oncologist, Dantec Hospital Joliot Curie, Dakar, November 13, 2012, and Abdoul Kassé, oncologist, Clinique de Mammelles, Dakar, November 13, 2012.

⁵³ UNAIDS, "Rapport de Situation sur la Riposte Nationale a L'épidémie de VIH/SIDA Sénégal: 2010-2011," March 2012, [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report\[1\].pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report[1].pdf) (accessed June 25, 2013), p. 14.

⁵⁴ *Ibid.*, p. 15.

⁵⁵ "Plan National de Developpement Sanitaire 2009-2018," Republique du Sénégal, Ministère de la Santé et de la Prevention, January 2009, <http://www.sante.gouv.sn/images/stories/pdf/pndsdxhuit.pdf> (accessed July 12, 2013).

⁵⁶ Kaiser Family Foundation, "Global Health Facts. Health Expenditure Per Capita," 2010, kff.org/global-indicator/health-expenditure-per-capita/ (accessed June 25, 2013). Note, Senegal spends about \$111 USD per capita, while its neighbors Mali spends \$69, Mauritania \$138, Guinea \$67, Guinea-Bissau \$82, and Gambia \$90. Some other Francophone states: Niger spends \$36, Central African Republic \$30, Togo \$74, and Burkina Faso \$92.

Table 1: Organization of Senegal’s Public Healthcare System⁵⁷

FACILITY	DESCRIPTION	LOCATION
National Hospital	The highest level of care available in the country.	Only in Dakar
Regional Hospital	These hospitals have general practitioners as well as some specialists, such as surgeons and gynecologists, on staff. They perform basic surgeries.	One per region
Centre de Santé (Health Center)	This is the lowest level of care where doctors are available. Health centers have inpatient facilities. Basic laboratory work can be done here. Maternal care is provided.	One per district
Poste de Santé (Health Post)	These are staffed by a nurse, a midwife, or both. In areas where nurses are not available, community healthcare workers may staff these posts.	Several per district
Case de Santé (Health Hut)	Community level of care, staffed by a community volunteer with basic medical training.	Available in rural communities

⁵⁷ Republique du Sénégal Direction de la Pharmacie et des Laboratoires, “Liste National de Medicaments et Produits Essentiels du Sénégal,” 2008, http://www.who.int/selection_medicines/country_lists/sen_eml_2008.pdf (accessed July 12, 2013), p. 6.

Senegal does not have a functioning public health insurance system. Some professionals have private insurance through their jobs, but the majority of patients pay out-of-pocket for almost all medical consultations, procedures and medications.⁵⁸ Consultation fees vary, but in general it costs about 3000 CFA (about \$6) to see a doctor at a regional hospital, 1000 CFA (about \$2) to see a doctor at a health center, and 500 CFA (about \$1) to see a nurse at a health center.⁵⁹ Several nurses told us that in general, only urgent, life-saving medications are kept on hand. All other items, including intravenous solutions, injections, and analgesics, need to be purchased at the pharmacy and brought back for the nurse or doctor to administer. Even patients who arrive in the emergency room in grave condition and those in post-operative care must wait, sometimes in severe pain, until a relative can go to the pharmacy for medicine.⁶⁰

Outside of the public health system, traditional medicine plays a significant role, especially in rural areas. Traditional medicine encompasses everything from spiritual healing ceremonies and incantations to treatment with herbs and plant extracts.⁶¹ According to patients and healthcare workers, traditional medicine is significantly cheaper, with fees said to be around 200 CFA (less than 50 cents), and often more accessible. However, there is no licensing or regulatory system for traditional medicine, and patients risk paying for fake cures, or for harmful substances.⁶²

The lack of a universal health coverage system means that patients are not protected from the financial ruin that often comes with chronic illnesses. Indeed, almost every patient we interviewed for this report spoke of financial problems, often resulting in an inability to afford potentially life-saving medications.

⁵⁸ Human Right Watch interview with doctors, Dakar, November 2012. Free treatment exists for certain pathologies, such as malaria, tuberculosis, and HIV/AIDS, and donor funding subsidizes certain facilities, such as the pediatric oncology ward at Dantec Hospital. Yet, the great majority of patients must pay for everything out of pocket including items such as gloves and disinfectant for surgery.

⁵⁹ Human Rights Watch interview with Alassane Moussa Niang, head doctor and general practitioner, Ziguinchor Centre de Santé, Ziguinchor, December 6, 2012.

⁶⁰ Human Rights Watch interviews with Amina Ndeye, head nurse of the emergency room, and Emmanuel Tendeng, head nurse of surgeries, Thiès Regional Hospital, Thiès, December 12, 2012, and El Hadj Sanné, head nurse of surgeries, Ziguinchor Regional Hospital, Ziguinchor (phone interview), and Dijoulaba Sow, nurse in emergency room, Dantec Hospital, Dakar, December 13, 2012.

⁶¹ Jori Lewis, "Senegal's Traditional Healers," *The World*, July 29, 2009, <http://www.theworld.org/2009/07/senegals-traditional-healers/> (accessed June 11, 2013).

⁶² Amanda Fortier, "Traditional, Western Medicine Treat Cancer in Senegal," *Voice of America*, February 5, 2011, <http://www.voanews.com/content/traditional-and-western-medicine-treat-cancer-in-senegal-115495589/157389.html> (accessed May 16, 2013).

The Decentralization of HIV Treatment

Many patients with HIV/AIDS need palliative care to address pain and other physical problems and mental stress. While treatment for cancer and other complex non-communicable diseases in Senegal is highly centralized, in response to HIV/AIDS, the government has followed WHO's call to "decentralize treatment from the capital city to rural provinces."⁶³ Senegal's low HIV prevalence rate is a success that has been attributed to the government's timely and organized response to the epidemic.⁶⁴

Through the 2002-2006 National Strategic Plan (Plan Strategique de Lutte Contre le SIDA), the Senegalese government and a coalition of national and international partners brought HIV testing and treatment to communities throughout the country.⁶⁵ With WHO's technical guidance, Senegal trained health care providers at the district level⁶⁶ and increased the number of voluntary counseling and testing sites.⁶⁷ A system of surveillance and information gathering was set up to allow the government to monitor progress, and identify regions where the epidemic is more aggravated (for example, Ziguinchor has a prevalence of 3 percent, Dakar at 0.6 percent and Saint Louis at less than 0.1 percent).⁶⁸

As of 2011, 656 community health providers have been trained.⁶⁹ There are also 1,023 Voluntary Counseling and Testing sites throughout the

⁶³ WHO, "Countries Showcase Benefits of Scaling up HIV/AIDS Services using WHO Approach," undated, <http://www.who.int/hiv/capacity/IMAI-ICASA/en/> (accessed June 11, 2013).

⁶⁴ Ibid.

⁶⁵ UNAIDS, "Rapport de Situation sur la Riposte Nationale a L'épidémie de VIH/SIDA Sénégal: 2010-2011," [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report\[1\].pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report[1].pdf), (accessed August 5, 2013), p. 17.

⁶⁶ WHO, "Countries Showcase Benefits of Scaling up HIV/AIDS Services using WHO Approach," undated, <http://www.who.int/hiv/capacity/IMAI-ICASA/en/> (accessed June 11, 2013).

⁶⁷ Daouda Diouf, "HIV/AIDS Policy in Senegal: A Civil Society Perspective," Open Society Foundation, 2007, http://www.opensocietyfoundations.org/sites/default/files/senegal_20071015.pdf, (accessed June 25, 2013), p. 16.

⁶⁸ UNAIDS, "Rapport de Situation sur la Riposte Nationale a L'épidémie de VIH/SIDA Sénégal: 2010-2011," [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report\[1\].pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SN_Narrative_Report[1].pdf), (accessed August 5, 2013), p. 23.

⁶⁹ Ibid., p. 50.

country,⁷⁰ 109 of which also offer anti-retroviral treatment (ARV).⁷¹ ARV medications are on Senegal's list of essential medicines and offered at the district level through health centers.⁷² Senegal was the first African country to establish a free ARV treatment program, with the government providing 40 percent of the funding and donors covering the rest. With decentralization and free anti-retroviral treatment, the percentage of AIDS patients who were able to access ARV treatment rose from 11 percent to 51 percent between 2004 and 2010.⁷³

Many HIV/AIDS patients are treated at Fann Hospital, a national hospital in Dakar, where palliative care services are available.⁷⁴ At the regional and district level however, there is no organized structure for palliative care.⁷⁵ In some rural areas, donations of HIV/AIDS care packages from NGOs and international health organizations may include palliative care medications, but the supplies are not consistent.⁷⁶ The government, in coordination with doctors specializing in HIV/AIDS, is in the process of revising the national HIV/AIDS policy.⁷⁷ Integrating palliative care in this policy and overall HIV/AIDS treatment would provide more comprehensive care for these patients.

⁷⁰ Ibid., p. 50.

⁷¹ Ibid., p. 39.

⁷² République du Sénégal Direction de la Pharmacie et des Laboratoires, "Liste National de Médicaments et Produits Essentiels du Sénégal," 2008, http://www.who.int/selection_medicines/country_lists/sen_eml_2008.pdf, p. 6.

⁷³ "Anti-Retroviral Coverage in Senegal," *Trading Economics*, undated, <http://www.tradingeconomics.com/senegal/antiretroviral-therapy-coverage-percent-of-people-with-advanced-hiv-infection-wb-data.html> (accessed June 11, 2013).

⁷⁴ Human Rights Watch interview with Fatou Ngom, HIV/AIDS specialist, Fann Hospital, Dakar, November 15, 2012.

⁷⁵ Ibid.

⁷⁶ Human Rights Watch interview with Babakar Mbaye, HIV/AIDS specialist, Goudomp Centre de Santé (Zigunchor), Dakar, November 29, 2012.

⁷⁷ Human Rights Watch interview with Fatou Ngom, November 15, 2012.

II. Palliative Care in Senegal: The Plight of Patients

I am in pain 24 hours a day. You cannot believe the pain I have all over my body. It is in my bones. I cannot have a real life without my medication.”

—Aliou Binta, a patient with terminal prostate cancer who uses oral morphine, November 2012.⁷⁸

During the course of Human Rights Watch’s research in Senegal, there was a shortage of morphine due to delays in importation—at that time only one hospital in the entire country imported morphine pills and there was only one local supplier of morphine syrup, so there were no alternatives to protect patients when those supply chains were interrupted.⁷⁹ Patients interviewed who were from outside Dakar, or came from Dakar hospitals without oral morphine, were given low level analgesics that usually cannot alleviate moderate to severe pain. The physical, psychological and social consequences of moderate to severe pain on individuals have been documented extensively by medical practitioners around the world. In interviews with Human Rights Watch, patients in Senegal who had experienced or were experiencing pain described these consequences, but they also described something that is not easily captured in quantitative studies: the personal and family tragedies that each case represents and the overwhelming sense of despair that many experience when trapped by pain, fear, and anguish.

The Suffering Caused by Untreated Pain

When Human Rights Watch interviewed Arame Diouf, a woman believed to be in her 40s and suspected to have liver cancer, she sat on a mattress on the floor, in a rigid upright position with her back pressed against the wall because that was how she could feel the “least amount” of pain.⁸⁰ Even so, she was shaking so badly from the pain from her sides and her chest that she could barely speak. Diouf was fortunate that her doctor at Grand Yoff Military Hospital was willing to visit her at home, since her pain left her bedridden. However, due to the morphine shortage, he could not properly alleviate her suffering.⁸¹

⁷⁸ Human Rights Watch phone interview with Aliou Binta, patient of Clinique de Mamelles, Dakar, November 28, 2012.

⁷⁹ Only Dantec Hospital imported morphine pills, and Dantec Hospital, Grand Yoff Hospital, and Principal Hospital imported morphine powder to make syrup from Val D’Afrique, a local supplier that in turn imported morphine powder from abroad.

⁸⁰ Human Rights Watch interview with Arame Diouf, patient, home interview, Dakar, December 2, 2012.

⁸¹ Human Rights Watch conversation with Oumar Ba, pulmonologist, Grand Yoff Hospital, Dakar, December 2, 2012.

Seynabou Binetou told Human Rights Watch that her 60-year-old father, Malick Binetou, was terminally ill with lung cancer. When he ran out of his medication during the oral morphine shortage, his daughter said he “spent the entire night crying.”⁸² Without oral morphine, he had to be hospitalized so that he could receive a morphine injection.

Sixty-five-year old Salimata Sylla, a diabetic for 15 years, had severe nerve pain in her foot, a common symptom of advanced diabetes. Her daughter, Coumba Ndiaye, was forced to watch her mother suffer for more than two months as medical doctors prescribed medications that were not sufficiently potent to control the pain. She said: “It was very hard for me to see her suffer. She could not sleep with the pain, and I did not sleep either.”⁸³ Eventually, doctors relieved Sylla’s pain by amputating her foot.

Khadija Sarr, a 45-year-old woman from Touba who doctors believed to have cancer, told Human Rights Watch that she had severe stomach pain and various other debilitating symptoms. Describing her pain, she said, “I [clutch] onto anything that is close to me because of the pain.” She said she has continually told doctors about this pain, but the low level analgesics they have given her have had no effect. Even after spending all her savings, she is still in agony: “I told my family not to bring me anymore because we have nothing left.”⁸⁴

Fatoumata Seck, a 33-year-old patient from Mali with advanced cervical cancer, told Human Rights Watch that the pain she was experiencing in her abdominal area was “infernal.” A mother who had given birth to six children, she said that it was “by far the worst pain” she had ever felt in her life.⁸⁵ Fatoumata had come to Senegal hoping to be cured, but she arrived during a morphine shortage. Without medication, her pain was so intense that she decided to return to Mali, where she had access to morphine.⁸⁶

Human Rights Watch did not interview young children directly, but there were also pediatric patients who suffered from untreated pain. “An infant with a swollen stomach who cries all the time—[doctors] should have known something is wrong, but they did not,”

⁸² Human Rights Watch interview with Seynabou Binetou, daughter of patient, Grand Yoff Hospital, Dakar, November 20, 2012.

⁸³ Human Rights Watch interview with Coumba Ndiaye, daughter of patient, Grand Yoff Hospital, Dakar, December 10, 2012.

⁸⁴ Human Rights Watch interview with Khadija Sarr, patient, Dantec Hospital Joliot Curie, Dakar, November 19, 2012.

⁸⁵ Human Rights Watch interview with Fatoumata Seck, patient, Dantec Hospital Joliot Curie, Dakar, December 14, 2012.

⁸⁶ Ibid.

said Khadidatou Doumbia, whose three-year-old niece, Joy Thierno, had suffered from persistent pain for two years, caused by a tumor on her kidney.⁸⁷ At the pediatric cancer ward in Dakar, some children would moan or whimper, but others lay quietly with their eyes tightly shut. Children, especially young children, often lack the vocabulary to express the severity of their condition.

The Impact on Healthcare Workers

The majority of healthcare workers interviewed for this report said that it was emotionally traumatizing not to be able to provide proper care for patients with severe pain. As a doctor from Thiès regional hospital said, “it’s a heavy burden for a doctor who sees someone suffer and he cannot do anything.”⁸⁸

Several healthcare workers mentioned the lack of availability of basic medications to relieve pain as a significant problem. A former general doctor at Tambacounda Regional Hospital said, “We need medication to help [relieve symptoms]. The person suffers for nothing—there is something that could help them, but it is not available.”⁸⁹ A nurse at Grand Yoff hospital in Dakar echoed the sentiment, saying, “Sometimes you do not have medication in place, and patients must wait—in this time the patient suffers. It is very difficult to see a patient suffer.”⁹⁰

Doctors who had received training in palliative care and pain management expressed particular frustration at being unable to utilize their knowledge. Guy Boukar Faye, a gynecologist in Ziguinchor, said, “I learned the treatment, but I cannot give it.” The director of the International Committee of the Red Cross in the same town said: “There is nothing to do for cancer patients here other than give them level 2 drugs [weak opioid pain killers] and send them home [to die].”⁹¹

⁸⁷ Human Rights Watch interview with Khadidatou Doumbia, aunt of patient, Dantec Hospital Pediatric Oncology, December 7, 2012.

⁸⁸ Human Rights Watch interview with El Hadj Malick Mbaye, surgeon, Thiès Regional Hospital, Thiès, December 12, 2012.

⁸⁹ Human Rights Watch interview with Cissokho Saiba, general doctor, formerly at Tambacounda Regional Hospital, phone interview, December 10, 2012.

⁹⁰ Human Rights Watch interview with Yvette Marie Therese Diatta, nurse in internal medicine, Grand Yoff hospital, Dakar, December 4, 2012.

⁹¹ Human Rights Watch interview with Thierry Parodi, Chef de Sous-délégation de Ziguinchor, International Red Cross, Ziguinchor, December 5, 2012.

Cancer Barriers and the Heightened Need for Palliative Care

The poor availability of preventative and curative care for cancer, and for other chronic illnesses, creates a heightened need for palliative care in Senegal because the great majority of people are diagnosed in advanced or terminal phases of illness during which pain is severe. In the course of our research, patients, their families, and healthcare workers told us about economic hardships and weaknesses in the health care system that limit access to cancer treatment. These barriers cause great suffering, and a great percentage of Senegalese cancer patients die because they accessed treatment too late, or because they could not afford curative treatment.

Diagnosis

Many people don't even think it's possible for a child to have cancer.

–Sokhna Ndiaye, psychotherapist, Dantec Hospital Pediatric Oncology Ward, November 2012.⁹²

Senegal's population largely lacks information about non-communicable diseases, early detection, and common symptoms, which frequently leads to delays in seeking medical care.⁹³ Technology is still very limited. Equipment required for diagnosis is often sophisticated, expensive and usually available in big cities, or only in Dakar.⁹⁴ Although Senegal is one of few countries in West Africa that has a radiation facility, it only has one radiation machine for the entire population of the country.⁹⁵ Certain biopsies and other tests have to be sent to France, significantly increasing the cost and delaying the onset of treatment, often by a month or more. For example, Aida Niang's daughter, eight-year-old Yacine Niang, had tests sent to France in May 2012, and received the results confirming that she had cancer in October 2012.⁹⁶

⁹² Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012.

⁹³ UN General Assembly, "Non-Communicable Diseases Deemed Development Challenge of Epidemic Proportions," Sixty-sixth General Assembly Plenary 3rd, 4th & 5th Meetings, 2011, <http://www.un.org/News/Press/docs/2011/ga11138.doc.htm> (accessed July 12, 2013); Abdoulaye Wade, President of Senegal, acknowledged the need to increase public awareness and prevention, and said it was "paramount for the public to understand the causes of non-communicable diseases."

⁹⁴ Ibid.

⁹⁵ Dantec Hospital had a Cobalt-60 machine. According to Dr. John Einck, an oncologist who visited the hospital to help update the center, it was a "form of radiation therapy which is no longer used in the Western world" and American doctors have only read about this machine in text books. Einck's team updated the machine with a new model. See, Radiating Hope, "Senegal Background," 2013, <http://www.radiatinghope.org/senegal-2012/> (accessed June 11, 2013).

⁹⁶ Human Rights Watch interview with Aida Niang, mother of patient, Dantec Hospital Pediatric Oncology, Dakar, November 20, 2012.

In addition to technological barriers, early symptoms of cancer are also frequently confused with other common pathologies, such as malnutrition, malaria or anemia.⁹⁷ Three-year-old Rama Ndiour was treated for yellow fever for several months in Zigunchor before being referred to Dakar, where she was diagnosed with abdominal lymphoma.⁹⁸ “Everybody kept saying it was malaria,” Issa Ngom said when he took his 11-year-old son, who actually had leukemia, to health posts.⁹⁹ When Alissatou Diallo’s four-year-old son, Demba, developed severe pain and swelling in his legs, doctors thought he had anemia and prescribed dietary supplements and basic pain killers. Diallo said, “You tell them that the medication does not work and they say, ‘you don’t know my job’.” After six months of tests and severe, unrelieved pain, “[doctors] said what he has is bizarre. There is no solution.” A visiting professor finally referred him to Dantec Hospital, where oncologists diagnosed him with bone cancer. By the time he began treatment however, his cancer had become too advanced, and he passed away a few weeks later.¹⁰⁰

Economic Barriers

“To treat one patient, you need to use 15-20 [individual] salaries. For rural areas, you would need the yearly revenue of 10 families to treat one case.”

—Dr. Abdoul Kassé, oncologist, Dakar, November 2012.¹⁰¹

With 46.7 percent of the population living at the poverty line, and 34 percent of living on less than \$1.25 dollars per day,¹⁰² many people will not pay for a doctor until symptoms become severe; at that point cancer is often already advanced. Pape Moustafha, a 67-year-old farmer from Touba (about 200 km from Dakar), told Human Rights Watch he had a tumor weighing a full kilogram on his shoulder, but did not go to a doctor until a religious leader in his community raised money to send him to Dakar.¹⁰³ Several patients interviewed had alarming symptoms, including large facial tumors, grossly swollen limbs, or abnormal bleeding, yet still delayed treatment for financial reasons.

⁹⁷ Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012.

⁹⁸ Human Rights Watch interview with Khadija Diatta, mother of patient, Dantec Hospital Pediatric Oncology, Dakar, November 26, 2012.

⁹⁹ Human Rights Watch interview with Issa Ngom, father of patient, Dantec Hospital Pediatric Oncology, Dakar, November 15, 2012.

¹⁰⁰ Human Rights Watch interview with Alissatou Diallo, Dantec Hospital Pediatric Oncology, Dakar, November 26, 2012.

¹⁰¹ Human Rights Watch interview with Abdoul Kassé, November 13, 2012.

¹⁰² The World Bank, “Senegal,” undated, <http://data.worldbank.org/country/senegal> (accessed June 11, 2013).

¹⁰³ Human Rights Watch interview with Pape Moustafha, patient, Dantec Joliot Curie, Dakar, December 7, 2012.

After diagnosis, cancer treatment generally involves numerous medical procedures over the course of an extended period of time. As a result, cost rapidly escalates as patients have to pay for consultation fees, prescriptions, tests, hospital room fees, operations, blood transfusions, chemotherapy, radiotherapy, and more. One grandmother of a pediatric cancer patient said,

The child's father sold a horse to support the treatment. After that, he sold a sheep. Then, I sold my bracelets and earrings. She needed surgery, but we still did not have enough money...¹⁰⁴

On top of medical fees, patients face mounting transportation costs. Cancer occurs in all 14 of Senegal's regions, but treatment is only available in Dakar. Some patients stay with relatives, but many have to rent housing or make a long and costly journey on a weekly or monthly basis. Lack of finances causes patients to skip appointments, or abandon treatment altogether.¹⁰⁵ An ENT in Thiès reported that of the 77 patients he diagnosed with cancer, only 34 returned for treatment, and only two could afford chemotherapy.¹⁰⁶

The Most Common Scenario: No Access to Palliative Care

When someone comes with an incurable disease, [healthcare workers] tell them to go back home. Doctors are not trained for this, especially in rural areas.
–Dr. Ahmadou Dem, an oncologist at Dantec Hospital, November 2012.¹⁰⁷

With old people, there is a culture of respect to let them rest at home, but there are not enough people for home care...then, the entire family is displaced by going to the hospital.

–Dr. Dia, a general practitioner at Ndioum Regional Hospital, November 2012.¹⁰⁸

¹⁰⁴ Human Rights Watch interview with Amina Dieng, grandmother of patient, Dantec Hospital Pediatric Oncology, Dakar, November 15, 2012.

¹⁰⁵ Human Rights Watch interview with doctors, Dakar, November 2012, and Rama Gueye, mother of patient, Dantec Hospital Pediatric Oncology, Dakar, November 29, 2012 and Ablaye Dia, father of patient and Eva Ndeye, mother of patient, Dantec Hospital Pediatric Oncology, Dakar, December 3, 2012.

¹⁰⁶ Human Rights Watch interview with Ndiasse Ndiaye, December 12, 2012.

¹⁰⁷ Human Rights Watch interview with Ahmadou Dem, November 13, 2012.

¹⁰⁸ Human Rights Watch interview with Aliou Dia, general practitioner, Ndioum Regional Hospital, Ndioum, November 22, 2012.

With only a few hospitals in Dakar offering any form of palliative care services, most patients who develop severe pain suffer without relief. The situation is particularly dire for patients from rural areas, where 70 percent of Senegal's population lives.¹⁰⁹ In the course of conducting research for this report, Human Rights Watch visited three of Senegal's 13 regions outside of Dakar. In each of these regions, we found that there were no palliative care services; some healthcare workers had no knowledge of what "palliative care" was, and there was no morphine, not even in hospitals. Sometimes, NGOs would donate limited packets of oral morphine, but it is not regularly stocked.¹¹⁰ The Senegalese military in Ziguinchor, where there is a low level armed conflict, has morphine in their infirmary, but only for use on military personnel.¹¹¹

Nurses and midwives at community health posts (postes de santé) in all three regions said that for patients with pain, they could only prescribe anti-inflammatory pain medicines and weak opioid analgesics, or refer them to higher level facilities, like health centers or hospitals.¹¹² Regional hospitals have fentanyl to use as anesthesia for operations, but for pain management, including post-operative, advanced cancer, and trauma patients, they, like the health posts, only have anti-inflammatory and weak opioid medications. Patients with severe pain must suffer, or go to Dakar.

Traveling to Dakar is a major burden, not only because it is costly and arduous, but also because it is intimidating for rural patients. Many speak neither Wolof nor French, the two primary languages spoken in Dakar.¹¹³ As the head nurse at one regional hospital said, "They know nothing of big cities. They say they'd rather die than go to Dakar."¹¹⁴ An expert on community development added: "The greater the distance from Dakar, the greater the expense and discomfort of travel, and the less likely patients will embark on the journey;" many end up dying in their homes, in pain, without any sort of care.¹¹⁵

¹⁰⁹ The Peace Corps, "About Senegal," February 12, 2012, <http://www.pcsenegal.org/pages/93-about-senegal> (accessed June 11, 2013).

¹¹⁰ Human Rights Watch interview with Babakar Mbaye, November 29, 2012.

¹¹¹ Human Rights Watch interview with Madior Diouf, military surgeon, December 5, 2012.

¹¹² Human Rights Watch interviews with nurses in Thiès, Podor and Ziguinchor, November and December 2012.

¹¹³ Human Rights Watch interview with Cirré Mamoudou Sy, head nurse, Podor Centre de Santé, Podor, November 22, 2012.

¹¹⁴ Ibid.

¹¹⁵ Human Rights Watch interview with Ahmadou Cisse, Director, ASRADEC (Association Senegalaise de Recherche et d'Appel au Developpement Communautaire), Dakar, November 26, 2012.

The Impact of Stock-Outs

Today it is calm because the children have morphine. When they do not, it is insufferable, not just for them but for us [doctors] as well.

–Dr. Claude Moreira, Head of Dantec Pediatric Oncology Ward,
November 2012.¹¹⁶

Even in Dakar, access to palliative care is difficult, not only because of limited supply, but also because of shortages. Injectable morphine is available at many national hospitals, but oral morphine can only be found at Dantec Hospital, Grand Yoff Hospital, Principal Hospital, and some private clinics. Dantec Hospital's central pharmacy is the only place in Senegal that fills oral morphine prescriptions for the public; the other two hospital pharmacies only dispense to their own patients. Shortages of morphine are common, and arise because the complicated authorization and importation process creates many opportunities for delays. Unexpected increases in patients and poor estimation of required stock are also factors; hospitals in Dakar treat patients from all over the country, and from neighboring countries as well, making it difficult to estimate need. Because there are only three hospitals that import oral morphine, and all import from the same supplier, there are no back up plans to mitigate deficits.

Indeed, when Human Rights Watch was in Senegal to research this report in November and December 2012, there was an oral morphine shortage that had lasted several months, and doctors estimated that new supply would not arrive until 2013. When Human Rights Watch returned to Senegal for follow up research in July 2013, there was another shortage of oral morphine that had lasted a week, and new stock arrived shortly before our departure.

During shortages, patients suffer tremendously, especially if they have been accustomed to taking medication. Numerous patients whose stories were described above were victims of the shortage. Alboury Seck, a patient with advanced prostate cancer, told Human Rights Watch that he had run out of medication and the pain was unbearable. He used to take 50mg of morphine three or four times a day. When the shortage began, he said he tried to conserve his remaining pills.

¹¹⁶ Human Rights Watch interview with Claude Moreira, July 8, 2013.

I tried to bear the pain for 2-3 days, and when I could not handle it, I would take one pill. I went to all the pharmacies and they do not sell it. I tried to use Tylenol, Motrin, it is the only thing I have with me. Two, three, four times a day, but it is not enough. Only the morphine works.¹¹⁷

When in considerable pain, he comes to Dakar and “begs [his physician] for something.”¹¹⁸ His physician keeps an emergency stock of opiate medicines that he gets as donations from hospitals in Europe, but the shortage had lasted so long that he had no more to give. Desperate, Seck tried sending his prescriptions to Paris, and even sent a relative abroad to find morphine to bring back to him, but with no success.

Several doctors told Human Rights Watch that they go to great lengths to try to limit the suffering of their patients during these shortages. They said that they create an emergency stock of morphine or other opioid pain relievers by asking relatives of deceased patients to return any left-over medications, asking doctors in France or elsewhere to collect donations and save returned opioid pain killers so they or their colleagues can collect them during visits, and asking doctors visiting from other countries to bring donations of opioid analgesics.¹¹⁹ These emergency stocks are then used during shortages or are given to patients who are too poor to buy the medications.

These emergency stocks, however, do not last long, and these doctors said they have to instruct patients to ration medications as much as possible by reducing the number of pills they take per day.¹²⁰ Doctors have to weigh the possibility that a reduced dosage will result in unrelieved pain with the possibility that the patient will run out of medication before new stock arrives. Arame Diouf, mentioned above, had been without morphine for a month before a doctor visited her in her home.¹²¹ The doctor gave her a packet of strong opioid pills that he had brought back from France, but instructed her to only take half a pill each day.¹²² Even then, he told Human Rights Watch that it was unlikely that the amount would last her until the end of the shortage.

¹¹⁷ Human Rights Watch phone interview with Aliou Binta, November 28, 2012.

¹¹⁸ Ibid.

¹¹⁹ Human Rights Watch interview with anonymous doctor, Dakar, November 2012.

¹²⁰ Human Rights Watch interview with anonymous doctor, Dakar, November 2012.

¹²¹ Human Rights Watch interview with Arame Diouf, patient, home interview, Dakar, December 2, 2012.

¹²² Human Rights Watch interview with anonymous doctor, Dakar, November 2012.

Doctors expressed their frustration at having to struggle to maintain an emergency stock and constantly keep track of morphine availability. One doctor at Grand Yoff said, "I am a doctor. I shouldn't have to [use my time] to go to France to look for medication..."¹²³ Regarding the shortage, another doctor at Dantec Hospital, remarked, "I am too busy to...investigate what is happening with the morphine."¹²⁴ Worrying about the supply of medicines creates an additional burden for doctors and other health care workers who are already overextended. Dr. Abdoul Kassé says, "I am a surgeon, but I also have to train students, give palliative care, monitor the supply chain of medications, and meet with government officials [on promoting cancer care]."¹²⁵ Dr. Claude Moreira adds, "There is a burn out of staff because there are so many roles to play, and you feel like everything falls into the water."¹²⁶

The Special Needs of Children

When a child is dying, people [focus only on curing] and ignore palliative care...we need palliative care for both the surviving and the dying.

–Dr. Claude Moreira, oncologist, Dantec Hospital, November 2012.¹²⁷

Children, just like adults, have a right to palliative care when suffering from a life-limiting condition. Often, healthcare workers and family members avoid giving opioid medication to children because they erroneously equate palliative care with "giving up" on the child's life. WHO however, defines children's palliative care as "the active total care of the child's body, mind and spirit," as well as support for the family—it is not limited to the terminally ill, and should be used *from time of diagnosis* to support curative care.¹²⁸

WHO has recognized the particular needs of children with regards to palliative care, including through its separate the WHO Model List of Essential Medicines for Children and its Pharmacological Guidelines on Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses.¹²⁹ Palliative care for children requires pediatric expertise

¹²³ Human Rights Watch interview with anonymous doctor, Dakar, November 2012.

¹²⁴ Human Rights Watch interview with Claude Moreira, December 10, 2012.

¹²⁵ Human Rights Watch interview with Abdoul Kassé, November 13, 2012.

¹²⁶ Human Rights Watch interview with Claude Moreira, November 14, 2012.

¹²⁷ Ibid.

¹²⁸ WHO, "WHO Definition of Palliative Care," undated, <http://www.who.int/cancer/palliative/definition/en/> (accessed July 12, 2013).

¹²⁹ WHO, "WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses," 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf (accessed June 27, 2013).

on child-specific symptoms and diseases. Cancer for example, may cause different symptoms in children than in adults, and certain cancers are more prevalent in or exclusive to children.

Pediatric palliative care includes efforts to assess and treat pain in children, and the provision of medicines in child-appropriate formulations, like morphine syrup. Children, especially young children, express their pain differently than adults do, and accurate assessment is essential to formulating the correct dosage and form of medication.¹³⁰ For pediatrics, WHO recommends a two-step ladder for pain treatment because intermediate analgesics, weak opioids, have not been proven as effective for children as for adults.¹³¹ Low level analgesics, like ibuprofen, should be used for mild pain, and strong opioids for more severe pain, with morphine being the “medicine of choice.”¹³²

Complete pediatric palliative care also requires expertise in child psychology and child protection because children often suffer from profound trauma and disorientation from serious illness, pain, hospitalization, and invasive medical procedures. Also, some severely ill children are vulnerable to exploitation, abuse, and neglect. Child appropriate methods of communication about the illness and prognosis, communication with the family, and support for the child through play, education, counseling and other activities, can help young patients and their families cope with the difficulties of chronic and life limiting illnesses.¹³³

In Senegal, pediatric palliative care is severely limited. Dantec Hospital’s Pediatric Oncology Ward in Dakar is the only facility in the country where children with cancer can receive treatment and pain relief. The ward also cares for children with illnesses other than cancer who suffer from severe pain because there are no other facilities that provide pediatric palliative care. Patients and their families from all over Senegal come to this ward, and many travel long distances. These children leave their families, friends, and schools behind, while their siblings often have to miss one or both parents for the duration of the treatment. For example, Mama Dhiediou and her eight-year-old daughter Fabenne

¹³⁰ WHO, “WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,” 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf (accessed June 27, 2013), p. 6.

¹³¹ *Ibid.*, p. 38-39.

¹³² *Ibid.*, p. 38.

¹³³ WHO, “National Cancer Control Programs: Policies and Managerial Guidelines,” 2002, <http://www.who.int/cancer/media/en/408.pdf> (accessed February 12, 2010) p. 85.

Dhiediou, are from Ziguinchor, and took an 18 hour ride on a ship to get to Dakar. Because Fabenne has a cancerous tumor on her cheek, she stayed for treatment. The two have been staying with relatives in Dakar for the past year, while Mama Dhiediou's two children, a three-year-old and a 10-year-old, remain with their aunt in Ziguinchor.¹³⁴

Each year, Dantec Pediatrics receives about 160 new cancer patients; Dantec's staff however, estimate that this figure represents only 20-25 percent of the total number of new pediatric cancer cases in Senegal. As a result, about 75-80 percent of children with cancer are "left to die alone," with no access to medical support.¹³⁵ According to Dr. Claude Moreira, the head of the pediatric oncology ward, the five-year survival rate at Dantec is approximately 60 percent.¹³⁶ When pediatric patients are terminally ill, they have the option of remaining in the hospital or returning home.

Most families choose to stay at Dantec because there are end of life symptoms, like severe pain, that require medical expertise to manage—expertise which is not available outside of Dakar. For example, Mouhammad Bandé's three-year-old son, Omala Bandé, was terminally ill and on morphine for his pain. Healthcare workers estimated that he would die in a matter of days; one staff member told Human Rights Watch, "If you ask [Omala] what he wants, he says he wants to go home." Their home however, is in Matam, near the border of Mauritania, and it would have taken them over 15 hours of travel by car. Healthcare workers said he would most likely die on the journey, and even if he lived, there would be no morphine there to ease his pain.¹³⁷ Omala passed away shortly after Human Rights Watch's interview, in July 2013.

¹³⁴ Human Rights Watch interview with Aida Niang, November 20, 2012.

¹³⁵ Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012. According to Ndiaye, statistics indicate that 600-800 children develop cancer in Senegal each year.

¹³⁶ Human Rights Watch interview with Claude Moreira, November 14, 2012.

¹³⁷ Human Rights Watch interview with Mouhammad Bandé, father of patient, and Sokhna Ndiaye, Dantec Hospital Pediatric Oncology Ward, Dakar, July 1, 2013.

The Importance of Psychosocial Care for Patients and their Families

While physical pain is often the most immediate symptom that patients with life limiting disease face, most also experience tremendous emotional, psychological, and spiritual pain. Addressing the psychosocial needs of patients and their families is a core function of palliative care. This involves communication between patient, family and healthcare providers about the illness, prospects for treatment and, in case the illness is incurable, discussion of the end of life. In countries with limited resources, caring for psychosocial needs may sometimes seem like a luxury, but for patients and their families, it is critical.

In 2011, the pediatric oncology unit at Dantec Hospital in Dakar hired their first and only psychotherapist, Sokhna Ndiaye, to work with patients, parents, and unit staff. Ndiaye holds weekly group therapy session for children with cancer, and biweekly meetings for parents. She also meets with the patients and families individually, providing them an outlet for their anxiety and pain. Ndiaye's office is a space where children can talk about their discomfort and vocalize their emotions freely. In her experience, "children protect their parents—even if they are not feeling well, they say nothing."¹³⁸

For example, Dieynaba Sene, the mother of 14-year-old leukemia patient Anita Sene, told Human Rights Watch that the low level pain medication had relieved her daughter's pain, but Anita herself admitted to us that it did not.¹³⁹ After Anita's death on June 25, 2013, Dieynaba told Human Rights Watch, "Anita would hide her pain. She would tell me she was fine, but I could tell she was hurting." Anita used to go to Ndiaye's office, and according to Dieynaba, "she would always come out smiling."

As about half of the unit's patients do not survive their battle with cancer, a core component of Ndiaye's job has been to work with doctors, patients, and families on breaking news about diagnosis and prognosis. Although the death

¹³⁸ Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012.

¹³⁹ Human Rights Watch interviews with Dieynaba and Anita Sene, Dantec Hospital Pediatric Oncology, Dakar, November 15, 2012.

of a child is always devastating, according to Ndiaye, if you prepare, it becomes “more bearable, and [patients] leave in a very different way because they have time to say goodbye.”¹⁴⁰ It has been challenging work, as doctors in Senegal receive no training on communication skills. According to Ndiaye, doctors “don’t know how to talk to people...we must tell [them] that your job is not just to cure.”¹⁴¹

Discussion of the prognosis may also help avoid futile expenditure, a significant concern for impoverished patients. When patients and their families are unaware of their diagnosis, they are likely to continue paying for futile treatment, often borrowing money or selling their property, pushing themselves deeper into debt. In Dakar, for example, we interviewed a woman who said she was searching for money for an x-ray because, “the doctors are still trying to figure out what is wrong with me.” Healthcare workers, however, told us that she was terminally ill with both cancer and AIDS, yet had not informed her that she had either illness or that no viable treatment options remained.¹⁴²

According to Dr. Claude Moreira, the head of the pediatric oncology unit at Dantec, Ndiaye has had a significantly positive impact on the well being of patients, their families and the clinic’s staff. Patients and families concurred. Anita Sene, the 14-year-old girl mentioned above, said, “Sokhna is the greatest help” she had received at Dantec Hospital.¹⁴³

While the children’s oncology ward at Dantec has a psychotherapist, there is no similar staff member at Joliot Curie, the cancer ward for adults. According to Ndiaye, she is one of approximately six psychotherapists in all of Senegal.¹⁴⁴ As Senegal seeks to roll out palliative care, it should also address psychosocial needs and the development of healthcare workers’ communication skills.

¹⁴⁰ Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012.

¹⁴¹ Ibid.

¹⁴² Human Rights Watch interview with Ndella Fanta, patient, Dantec Hospital Joliot Curie, Dakar, December 7, 2012.

¹⁴³ Human Rights Watch interviews with Dieynaba and Anita Sene, November 15, 2012.

¹⁴⁴ Human Rights Watch interview with Sokhna Ndiaye, November 12, 2012.

III. Exploring the Causes of the Palliative Care Gap

The World Health Organization has urged countries to adopt national or state policies that support pain relief and palliative care; enact educational programs for the public, healthcare personnel, regulators, and other relevant parties; and modify laws and regulations to improve the availability and accessibility of drugs, especially opioid analgesics.¹⁴⁵ It has noted that such measures, fundamental for the development of palliative care, “cost very little but can have a significant effect.”¹⁴⁶ WHO has also developed specific standards that are relevant for children’s palliative care, such as the WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,¹⁴⁷ and the list of Essential Medicines for Children, and on pediatric cancer care.

WHO has also pointed out that in “countries with limited resources, it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advanced disease and urgently in need of symptom control must suffer without relief.”¹⁴⁸ It recommends that countries prioritize implementing palliative care services in the community—offering care at people’s homes rather than at healthcare institutions—where it can be provided at low cost and where people with limited access to medical facilities can be reached, and in medical institutions that deal with large numbers of patients requiring palliative care services.¹⁴⁹

The World Health Organization’s recommendations correspond closely with several core obligations, which countries must meet regardless of resource availability, under the right to health. The Committee on Economic, Social and Cultural Rights (CESCR), which monitors implementation of the right to health as articulated in the International Covenant on

¹⁴⁵ WHO, “Cancer Pain Relief: With a Guide to Opioid Availability,” 1996, <http://whqlibdoc.who.int/publications/9241544821.pdf> (accessed August 5, 2013), p. 3.

¹⁴⁶ *Ibid.*

¹⁴⁷ WHO, “WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,” 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf (accessed June 27, 2013).

¹⁴⁸ WHO, “National Cancer Control Programme: Policies and Managerial Guidelines”, Second Edition, 2002, <http://www.who.int/cancer/media/en/408.pdf> (accessed August 5, 2013), p. 86.

¹⁴⁹ *Ibid.*, pp. 91-92.

Economic, Social and Cultural Rights (ICESCR),¹⁵⁰ has held that countries must adopt and implement a national public health strategy and plan of action, and ensure access to essential drugs as defined by WHO.¹⁵¹ It has identified providing appropriate training for health personnel as an obligation “of comparable priority.”¹⁵²

To date, the Senegalese government has not implemented these recommendations. There have been few policy initiatives to support the development of palliative care services; training for healthcare workers in palliative care and pain management remains extremely limited; Senegal’s supply and distribution system for strong opioid analgesics does not ensure an uninterrupted supply of these medications; and drug control regulations are unnecessarily restrictive, resulting in inaccessibility of medications for patients. As a result, Senegal performs poorly in each of three areas highlighted by WHO.

Yet, there appears to be a growing acknowledgement in Senegal that palliative care is an essential health service that has been neglected. In 2011, a group of prominent Senegalese doctors founded the Association Sénégalaise de Soins Palliatifs (ASSOPA) to promote palliative care in the country. Following consultations with some of the specialists involved with ASSOPA, the government included oral morphine pills in its essential medicines list in late 2012, a step that should improve its supply and distribution.¹⁵³ In various meetings, government officials expressed a desire to Human Rights Watch to take steps to ensure the availability of palliative care and openness to working with civil society to promote its development.¹⁵⁴

¹⁵⁰ International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force January 3, 1976, art. 11; also in the Convention on the Rights of the Child (CRC), G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, art. 12.

¹⁵¹ UN Committee on Economic, Social and Cultural Rights, “Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights,” General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000), [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358boe2c125691500509obe?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358boe2c125691500509obe?Opendocument) (accessed May 11, 2006), para. 43.

¹⁵² *Ibid.*, para 44(f).

¹⁵³ Human Rights Watch interview with Oumar Ba, pulmonologist, Grand Yoff Hospital, Dakar, November 26, 2012.

¹⁵⁴ Human Rights Watch interview with Boubakar Gueye, Head of Non-Communicable Diseases, Ministry of Health, Dakar, November 16, 2012.

Policy

Since [they] are going to die, it doesn't matter. It doesn't matter if they are going to die in two days or two months.¹⁵⁵

–Sophie Coulbary, the Secretary General of the Senegalese Association for Palliative Care, on why palliative care is neglected by healthcare and health policy, November 2012.¹⁵⁶

To successfully address the problems described above, a concerted and coordinated effort by a broad range of governmental and other stakeholders is needed: to develop a decentralized model that makes palliative care accessible to patients in rural areas as well as in tertiary care institutions; to ensure a reliable supply of opioid analgesics and adequate distribution to healthcare facilities; to reform outdated drug regulations; and to incorporate palliative care into instruction for health workers. The WHO Global Action Plan for the Prevention and Control of Non-Communicable Diseases for 2013–2020, approved in May 2013, urges states to develop such a strategy.¹⁵⁷

At present, Senegal does not have a national palliative care policy or strategy. Although the government has undertaken some efforts to develop a national cancer control program, at present no such program is operational.¹⁵⁸ Similarly, there are no national programs for other chronic illnesses, such as diabetes and cardiovascular disease.¹⁵⁹ The current national HIV/AIDS strategy makes no references to palliative care, and at time of writing, the draft of the new strategy still did not include palliative care.¹⁶⁰ As a result, Senegal lacks a vision for how palliative care services can be implemented in the country or any kind of coordinated efforts to improve palliative care.

¹⁵⁵ Human Rights Watch interview with Sophie Aminata Coulbary, Anesthesiologist, Pikine Hospital, Dakar, November 13, 2012.

¹⁵⁶ Ibid.

¹⁵⁷ WHO, “Global Action Plan for the Prevention and Control of Non-Communicable Diseases for 2013–2020,” 2013, http://www.who.int/nmh/events/2013/revised_draft_ncd_action_plan.pdf (accessed August 5, 2013).

¹⁵⁸ Human Rights Watch interview with Abdoul Kassé, November 13, 2012 and e-mail correspondence with Abdoul Kassé, May 6, 2012. Dr. Abdoul Kassé told Human Rights Watch that he participated in the development of two cancer policies for the Senegalese government, but that neither was financed or implemented. See also, WHO Country Profile 2011, “Senegal,” http://www.who.int/nmh/countries/sen_en.pdf (accessed July 29, 2013).

¹⁵⁹ WHO Country Profile 2011, “Senegal,” http://www.who.int/nmh/countries/sen_en.pdf (accessed July 29, 2013).

¹⁶⁰ E-mail from Barbara Sow, Family Health International, June 2, 2013; “We have reviewed the last version of the National HIV Plan and there is still no section on palliative care.”

Given Senegal's decentralization and free provision of treatment for HIV/AIDS, malaria, and tuberculosis, and its rural rotating nurses (“Dispenser de Soins au Domicile”) who drive to villages and health huts dispensing care for malaria and vaccines,¹⁶¹ the country has the resources and capability to develop palliative care services in the community. A strategy that utilizes Senegal's existing resources to expand access to care could easily capitalize on the existing health infrastructure to develop palliative care at the community level.

Senegal's Essential Medicines List

The Direction de la Pharmacies et des Medicaments (DPM) is the government body in charge of regulating Senegal's list of essential medicine. As mentioned, the government did take an important step forward by adding oral morphine tablets and tramadol, a weak opioid, to the 2012 essential medicines list.¹⁶² Nevertheless, the list still has two major shortcomings that limit palliative care accessibility, especially for rural patients and children.

First, the list restricts morphine to regional and national hospitals,¹⁶³ which are only located in Dakar and main regional cities.¹⁶⁴ Pharmacists and government officials at the DPM have interpreted the list differently. Numerous healthcare workers and regional pharmacists have told Human Rights Watch that it is against the law to stock morphine outside of hospitals. However, Papisaliou Diop, the director of the DPM, said that all facilities are allowed to stock it, but only hospitals can sell it to outpatients.¹⁶⁵ According to Diop's interpretation, nurses at health posts, and even community volunteers, could keep oral morphine on stock as long as they have doctor supervision. Both interpretations of the list restrict the development of palliative care services at the community level. Health posts are only staffed by nurses, and while they are affiliated with health centers, doctors do not supervise them directly. Preventing lower level health facilities from selling oral morphine forces patients to travel to the facility and pay a consultation fee each time they need their dosage—which may be multiple times per day. These drugs need to be available and accessible at more levels of care.

¹⁶¹ Human Rights Watch interview with Cirré Mamoudou Sy, November 22, 2012 and Ahmadou Cisse, November 26, 2012.

¹⁶² “Liste Nationale de Medicament et Produits Essentiels du Senegal,” Direction de la Pharmacie et des Laboratoires, 2012. The medications added are morphine hydrochlorate in 10 and 30 mg tablets and tramadol (trabar) in 100mg/2ml.

¹⁶³ Ibid.

¹⁶⁴ The 14 regional capitals in Senegal, which bear the same name as the region, are Dakar, Diourbel, Fatick, Kaffrine, Kaolack, Kédougou, Kolda, Louga, Matam, St. Louis, Sédhiou, Tambacounda, Thiés and Ziguinchor. Outside of Dakar, regional hospitals are only located in the following cities: Diourbel, Fatick, Kaolack, Kolda, Louga, St. Louis, Ndioum, Oros Sogui, Tambacounda, Thiés and Ziguinchor. See “Les Structures de Santé,” Ministère de la Santé et de l'Action Sociale de Sénégal, 2011, http://www.sante.gouv.sn/index.php?option=com_content&view=article&id=1296&Itemid=768 (accessed August 24, 2013).

¹⁶⁵ Human Rights Watch interview with Papisaliou Diop, Director, Direction de la Pharmacie et des Medicaments, Dakar, July 11, 2013.

The Example of Uganda

In 1998, Ugandan government officials, representatives of nongovernmental organizations, and WHO met at a conference entitled “Freedom from Cancer and AIDS Pain” to discuss how to make pain treatment available to the population. At the meeting, participants agreed to take a series of simultaneous steps to deal with key barriers:

- The Ministry of Health and WHO were to develop a national palliative care policy, and cancer and AIDS pain relief policies.
- The Government initiated meetings, which endorsed a nine-month full time course training at Hospice Africa Uganda, to increase the number of prescribers.
- The drug control authority was to develop new drug regulations, update the essential drug list, conduct estimates of the medical need for morphine, and request an increased national allowance from the INCB.

In addition, a commitment was made to ensure coordination of palliative care activities for AIDS and cancer, to set up multidisciplinary clinics for cancer patients, to increase awareness of palliative care among the population, and to identify a demonstration project in Uganda’s Hoima District where Little Hospice Hoima, a branch of palliative care organization of Hospice Africa Uganda, was already active.¹⁶⁶

In its five-year Strategic Health Plan for 2000-2005, the government stated that palliative care was an essential clinical service for all Ugandans, becoming the first nation in Africa to do so. It also added liquid morphine to its essential drug list, adopted a new set of Guidelines for Handling of Class A Drugs for healthcare practitioners—also a first in Africa—and, in 2003, authorized prescribing of morphine by nurses who have been trained in palliative care.

By early 2009, 79 nurses and clinical officers had received training on pain management and been authorized to prescribe oral morphine; several thousand healthcare workers had attended a short course on pain and symptom management; and 34 out of 56 districts in Uganda had oral morphine available and in use. The initiatives that Uganda took can serve as a model for Senegal and other resource strapped countries that need to begin developing palliative care services. As Uganda’s progress shows, palliative care is easy and cheap to administer, but the government needs to have political will and organization to develop a strategy of implementation.

¹⁶⁶ Jan Stjernsward, “Uganda: Initiating a Government Public Health Approach to Pain Relief and Palliative Care,” *Journal of Pain and Symptom Management*, vol. 24, no. 2 (August 2002).

Rwanda's National Palliative Care Strategy

In 2010, Rwanda became the first African country to adopt a stand-alone palliative care policy. While some countries have palliative care policies that are inserted as subsections of a national policy for HIV/AIDS, cancer, or other illness, a stand-alone palliative care policy is more effective because the government can focus specifically on palliative care and its development in a variety of disciplines.¹⁶⁷ Rwanda's policy's goal is to ensure that all people with life-limiting illnesses in Rwanda will have access to quality palliative care services delivered in an affordable and culturally appropriate manner by 2020.¹⁶⁸ It seeks to achieve this goal by promoting the "development or improvement of palliative care across the different services levels, within the organizational capacity of various service providers."¹⁶⁹ The policy is accompanied by a "Five-Year Strategic Plan for Palliative Care for Incurable Diseases," which sets goals for the period between 2010 and 2014. According to the strategic plan, the ministry of health will regularly monitor and report on progress toward the implementation of the policy.¹⁷⁰

Since the adoption of the policy in 2010, Rwanda has had a home based hospice service that made over 700 patient visits in 2012 alone. With support from Hospice Without Borders, an organization from United States committed to supporting the clinical home care service, the hospice service has also provided palliative care training to over 500 nurses, doctors and community healthcare workers. The organization works with Kibagabaga Hospital, which is the center of excellence in palliative care and the first district hospital to succeed in integrating this new approach in various inpatients services. Moreover, a cancer center in the Butaro district opened a new wing to manage a large number of patients, who required diagnosis and treatment.¹⁷¹

¹⁶⁷ "Standards and Guidelines for the Provision of Palliative Care for Incurable Diseases," Rwanda Ministry of Health, August 2010 and Grace Munene, "Rwanda One Year On, What Has Changed Since the Launch of a Stand-Alone Palliative Care Policy?," *Ehospice*, October 23, 2012, <http://www.ehospice.com/africa/ArticlesList/Rwandaoneyearonwhathaschangedsincethelaunchofstandalonepalliativecarepolicy/tabid/2673/ArticleId/1259/language/en-GB/Default.aspx#.UbgBTufD4oM> (accessed June 11, 2013).

¹⁶⁸ "Standards and Guidelines for the Provision of Palliative Care for Incurable Diseases," Rwanda Ministry of Health, August 2010, p. iii.

¹⁶⁹ *Ibid.*, p. 7.

¹⁷⁰ "Five-Year Strategic Plan for Palliative Care for Incurable Diseases," Rwanda Ministry of Health, August 2010.

¹⁷¹ Irene Nayebare, "Butaro Cancer Centre Opens New Wing," *The New Times*, August 22, 2013, <http://www.newtimes.co.rw/news/index.php?a=69744&i=15457> (accessed September 21, 2013).

Secondly, and contrary to WHO's recommendations, the list does not include liquid oral morphine. Smaller children and adults with mouth and throat cancers often cannot swallow capsules, so morphine syrup is essential to managing their pain.

During research in Senegal in July 2013, Human Rights Watch spoke with government officials at the DPM who said that they are considering adding morphine syrup to the next revision of the list. Pharmacists have not been able to find a vendor of morphine syrup, and have successfully made their own morphine syrup by using morphine powder. The DPM however, claims that "morphine powder is not a medicine, it is a chemical," and therefore does not belong on the list.¹⁷² If the powder is not on the list, the National Pharmacy will not import it, and hospitals will have to import it themselves, through a complicated process that often results in shortages. It is crucial that the government ensures that the National Pharmacy takes charge of procuring either morphine syrup or morphine powder.

Training

We are not focused on palliative care because we are not used to it. It's not part of training or in courses. We never think much about suffering.

–Papasalio Kame Gaye, head doctor and pediatrician, Ndioum Regional Hospital, November 2012.¹⁷³

A dearth of training on palliative care means that many health care workers do not fully understand palliative care or have the skills to provide it. The lack of education also enables health care workers to continue to subscribe to a variety of myths and misconceptions about strong opioid analgesics.

Under the right to health, governments must take reasonable steps to ensure health care workers have appropriate training. As an integral part of care and treatment for cancer, HIV, and various other chronic illnesses, countries need to ensure that basic instruction on palliative care and pain management is part of undergraduate medical studies, nursing school, and continuing medical education. Specialized instruction should be available for healthcare workers who pursue a specialization in oncology, HIV and AIDS,

¹⁷² Human Rights Watch interview with Papasalio Diop, July 11, 2013.

¹⁷³ Human Rights Watch interview with Papasalio Kame Gaye, head doctor and pediatrician, Ndioum Regional Hospital, November 22, 2012.

and other disciplines where knowledge of pain management and palliative care is a key part of treatment.

Medical Education in Senegal

There are doctors who have never prescribed [morphine]...they think it's normal. They accept suffering.

–Dr. Oumar Ba, pulmonologist at Grand Yoff, November 2012.¹⁷⁴

Dr. Boubakar Gueye, former head of the non-communicable diseases department at the Ministry of Health, said that lack of training for healthcare workers was a significant obstacle to palliative care development.¹⁷⁵ Madické Gueye, head of internal medicine at Grand Yoff Hospital, specifically noted that lack of familiarity with opiates is the greatest barrier.¹⁷⁶ He said, “Before administering a product, you must know it. Doctors must know why we use a drug and how to use it.”¹⁷⁷ Most of the doctors who are currently active in providing palliative care received their training outside of Senegal, usually in France.¹⁷⁸ Several doctors also learned by attending post graduate training in Burkina Faso, Sudan and Uganda.¹⁷⁹ It is imperative however, that such training become available in Senegal.

Senegal has both public and private medical schools. The state monitors both types of schools to ensure that essential programs are taught, but the faculty has flexibility to structure the curriculum and add additional classes. For example, the faculty at Dakar's Cheikh Anta Diop Medical School added a course on oncology.¹⁸⁰ After medical school, many doctors go on to specialize in a specific area of medicine.¹⁸¹

Several recently graduated doctors said that they had received basic training on pain relief, but that there was no specialized training for palliative care. All of the faculty members of

¹⁷⁴ Human Rights Watch interview with Oumar Ba, November 26, 2012.

¹⁷⁵ Human Rights Watch interview with Boubakar Gueye, November 16, 2012.

¹⁷⁶ Human Rights Watch interview with Madické Gaye, head of internal medicine, Grand Yoff Hospital, Dakar, December 4, 2012.

¹⁷⁷ Ibid.

¹⁷⁸ Human Rights Watch interview with oncologists, Dakar, November 2012.

¹⁷⁹ Human Rights Watch interview with Sophie Aminata Coulbary, November 13, 2012, and Oumar Ba, November 26, 2012.

¹⁸⁰ Human Rights Watch interview with Ahmadou Dem, July 2, 2013.

¹⁸¹ Human Rights Watch interview with Sophie Aminata Coulbary, November 13, 2012.

medical schools that Human Rights Watch interviewed confirmed that there are no classes on palliative care in the medical school curriculum, and no stand alone classes on pain management.¹⁸² Pain management is taught as a component of classes on physiology and anesthesiology.¹⁸³ There are no specialization programs for palliative care because it is not yet recognized as a specialty or subspecialty of medicine.¹⁸⁴ Thus, while doctors may have basic knowledge of pain relief, they usually do not have comprehensive understanding of pain evaluation and its application to the chronically ill.

This year however, Dr. Claude Moreira, head of Dantec Hospital's Pediatric Oncology Ward and professor at Cheikh Anta Diop Medical School and Thiès University, began teaching a class on children's palliative care.¹⁸⁵ Dr. Ahmadou Dem, oncologist at Dantec Hospital's Joliot Curie Institute and professor at Cheikh Anta Diop Medical School, is preparing a course on geriatrics and palliative care, which will become a mandatory part of the school's curriculum starting this fall.¹⁸⁶ Additionally, Bernard Diop, a retired doctor and HIV specialist, is in the process of organizing a specialization in palliative care at Thiès University.¹⁸⁷ This progress is a laudable step forward in medical education in Dakar and Thiès, but it is still necessary for the government to integrate palliative care into the country's medical curriculum requirements as a whole.

In addition to a lack of palliative care training in medical schools, Senegal also has no regular continuing medical education courses in palliative care or pain management.¹⁸⁸ As a result, practicing physicians do not receive updated knowledge on these disciplines. Dr. Ahmadou Dem, an oncologist at Dantec Hospital, pointed out that, "most doctors from my era were not trained in palliative care, so there is a deficit of knowledge."¹⁸⁹ Dr. Dem, and many other members of ASSOPA, graduated from medical school about 20 years ago. According to him and his colleagues, medical schools used to actively discourage the use of strong opioid

¹⁸² Human Rights Watch interview with doctors who teach at medical schools, Dakar, November 2012 and July 2013.

¹⁸³ Human Rights Watch interview with Ahmadou Dem, November 13, 2012 and Boubakar Gueye, November 16, 2012.

¹⁸⁴ Human Rights Watch interview with doctors who teach at medical schools, Dakar, November 2012 and July 2013.

¹⁸⁵ Human Rights Watch interview with Claude Moreira, July 1, 2013.

¹⁸⁶ Human Rights Watch interview with Ahmadou Dem, July 1, 2013.

¹⁸⁷ Human Rights Watch interview with Bernard Diop, HIV/AIDS specialist, Dakar, November 20, 2012.

¹⁸⁸ Human Rights Watch interview with Sophie Aminata Coulbary, November 13, 2012.

¹⁸⁹ Human Rights Watch interview with Ahmadou Dem, November 13, 2012.

analgesics, inaccurately teaching students that morphine is a dangerously addictive drug of last resort and emphasizing potential side effects, such as respiratory depression.¹⁹⁰

The head doctor at one regional hospital, for example, said that he had never used morphine during his career because he was “afraid to.”¹⁹¹ He said that his medical school had taught him that morphine was a “dangerous narcotic,” only to be used in extreme emergencies. Knowledge of and best practice standards in pain management have evolved significantly in the last few decades, making continuing education programs in the subject essential.

Nursing Education

“One cannot say they are not trained, but that they are not *sufficiently* trained.”

–Dr. Madické Gaye, head of internal medicine, Grand Yoff Hospital,
December 2012.¹⁹²

In a country like Senegal, with a small ratio of one medical doctor per 11,000 individuals, nurses play an especially important role in the provision of palliative care. Even in major hospitals, nurses are closest to the patients and their families and regularly charged with dispensing medication and monitoring patients.¹⁹³ While they may not be able to provide the full scope of palliative care services, with training they can assess pain, provide basic care, and refer patients for more complex interventions. In Uganda for example, the government has been training nurses to prescribe opioids to patients, greatly expanding access to palliative care in communities (see text box, “The Example of Uganda,” in Section III, Exploring the Causes of the Palliative Care Gap).

In Senegal however, palliative care is barely addressed in nurse training.¹⁹⁴ To become a nurse, it is necessary to complete an undergraduate degree, and then complete three years

¹⁹⁰ Human Rights Watch interviews with doctors, Senegal, November and December 2012.

¹⁹¹ Human Rights Watch interview with Papasaliou Kame Gaye, November 22, 2012.

¹⁹² Human Rights Watch interview with Madické Gaye, December 4, 2012.

¹⁹³ Human Rights Watch interview with Ahmadou Dem, July 2, 2013.

¹⁹⁴ Human Rights Watch interview with Babakar Ba and Moussa Diongue, nurses, Dantec Hospital Joliot Curie, Dakar, July 2, 2013.

in nursing school. Like doctors, nurses can also seek additional education for a specialty, but there is no specialty in palliative care.¹⁹⁵

Nursing education is decentralized, with public and private nursing schools in every region. While they do teach basic pain management and some palliative care, instruction is limited. In general, there are no stand-alone classes for either discipline.¹⁹⁶ Palliative care is taught as a small component of the “nursing care” class; most nurses received only about two to four hours of education on palliative care in their schools.¹⁹⁷ Dr. Abdou Omar Fall, an anesthesiologist at Ziguinchor Regional Hospital, notes that, “morphine has side effects, so we need to monitor patients, but our nurses do not have the training.”¹⁹⁸ Madické Gaye, a former nurse who is now a doctor, wrote his medical school thesis on pain management. In his experience, most nurses cannot properly evaluate pain; they do not understand the WHO ladder in giving pain medication, and many do not realize that lack of pain management is a problem.¹⁹⁹

Nurses with a specific interest in palliative care have little choice but to study by themselves. Two nurses, Amory Diop and Abdoulaye Gueye, told Human Rights Watch that they had to “train themselves” in palliative care through learning on the job while working with patients in severe pain.²⁰⁰ Gueye runs a home care service at Grand Yoff hospital, predominantly for patients with diabetes, while Diop used to run a general home care service at Dantec Hospital²⁰¹ Diop recently organized palliative care classes for the nursing school curriculum, and now teaches it at Dakar’s National Nursing School (École Nationale des Infirmières de l’Etat).²⁰² He hopes that other nursing schools will follow suit and establish palliative care programs.²⁰³

¹⁹⁵ Ibid.

¹⁹⁶ Ibid.

¹⁹⁷ Ibid.

¹⁹⁸ Human Rights Watch interview with Abdou Omar Fall, anesthesiologist, Ziguinchor Regional Hospital, Ziguinchor, December 5, 2012.

¹⁹⁹ Human Rights Watch interview with Madické Gaye, December 4, 2012.

²⁰⁰ Human Rights Watch interview with Amory Diop, head nurse, Rufisque Hospital, Rufisque, November 26, 2012, and Abdoulaye Gueye, nurse, Grand Yoff Hospital, Dakar, December 4, 2012.

²⁰¹ Human Rights Watch interview with Amory Diop, November 26, 2012, and Abdoulaye Gueye, December 4, 2012.

²⁰² Human Rights Watch interview with Amory Diop, November 26, 2012.

²⁰³ Ibid.

Notably, Senegal has rotating nurses called “Dispensers de Soins au Domicile.”²⁰⁴ Equipping these rotating nurses with oral opiates and basic training on dosage and administration would be a cheap, easy, and effective way to greatly expand access to palliative care in rural areas.

Consequences of Inadequate Training

Lack of training inhibits healthcare providers from administering palliative care services, but it also results in false assumptions about palliative care and failure to understand patients’ needs for pain treatment.

Misconceptions about Morphine Use

Over the course of our research, various doctors and government officials expressed concerns about negative side effects that morphine might have on patients, such as dependence and respiratory depression. While WHO has noted that these “greatly exaggerated fears of addiction”²⁰⁵ are unwarranted because studies have shown that only 0.05% of patients using opiates for medical purposes develop dependence syndrome;²⁰⁶ therefore, “the risk of [drug] dependence should not be a factor in deciding whether to use opioids to treat [patients].”²⁰⁷ Withdrawal can be prevented by gradually reducing the dose instead of making an abrupt interruption.²⁰⁸ Following best practices for prescribing opioid analgesics, proper monitoring, and follow-up with patients, can minimize the risk of misuse and side effects; most side effects can be easily managed with inexpensive medications.²⁰⁹

Access to education will give healthcare workers the knowledge and confidence to administer these medications, and will also raise awareness of the purpose of morphine and palliative care. Both healthcare workers and government officials told Human Rights Watch that they had thought morphine was only for the terminally ill, or more specifically, only necessary for advanced cancer patients. One official at the National Pharmacy

²⁰⁴ Human Rights Watch interview with Cirré Mamoudou Sy, November 22, 2012 and Ahmadou Cisse, November 26, 2012.

²⁰⁵ WHO, “Achieving Balance in Opioid Control Policy: Guidelines for Assessment,” 2000, p. 1.

²⁰⁶ WHO, “Ensuring Balance in National Policies on Controlled Substances,” 2011, http://www.unodc.org/docs/treatment/Pain/WHO_ensuring_balance_controlled_substances.pdf (accessed July 17, 2013), p. 15.

²⁰⁷ WHO, “Achieving Balance in Opioid Control Policy: Guidelines for Assessment,” 2000, p. 8.

²⁰⁸ WHO, “WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,” 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf (accessed June 27, 2013), p. 13.

²⁰⁹ WHO, “Achieving Balance in Opioid Control Policy: Guidelines for Assessment,” 2000.

explained that regional pharmacies do not need morphine because, “morphine is for people with terminal cancer, and those people are taken care of only in Dakar.”²¹⁰

As emphasized repeatedly throughout this report, palliative care is treatment for chronic pain and other distressing symptoms, necessary from the time of diagnosis, utilized to support curative care, and applicable to a wide range of illnesses, including HIV/AIDS and diabetes. Additionally, patients with advanced cancer exist everywhere in Senegal. Those who cannot afford treatment in Dakar, or otherwise die in their homes, need access to palliative care medication in their communities.

Failure to Recognize Palliative Care Needs

Pain is subjective. People do not understand the pain that others feel.

Sometimes they think that it is a joke.

–Dr. Madické Gaye, head of internal medicine, Grand Yoff Hospital,
December 2012.²¹¹

Patients prefer to not speak about pain, they’d prefer to die—the people here are proud.

–Cirrè Mamoudou Sy, head nurse at Ndioum Regional Hospital,
November 2012.²¹²

Though most healthcare workers told Human Rights Watch that there are numerous patients with severe pain in their facilities, some healthcare workers, seemed to trivialize the seriousness of pain, reflecting their lack of knowledge about palliative care and pain management. Some maintained that patients only have pain psychologically or that all pain can be relieved with a combination of weak pain killers.²¹³ An anesthesiologist in Thiès who worked in maternity claimed that there is “no pain that cannot be resolved” with low level opioids or anti-inflammatory pain killers.²¹⁴ This statement of course, is contrary to medical findings, and scientific fact, and patient experience.

²¹⁰ Human Rights Watch interview with anonymous official, PNA, Dakar, December 14, 2012.

²¹¹ Human Rights Watch interview with Madické Gaye, December 4, 2012.

²¹² Human Rights Watch interview with Cirrè Mamoudou Sy, November 22, 2012.

²¹³ Human Rights Watch interviews with anonymous healthcare workers, Podor and Rufisque, November 28, 2012.

²¹⁴ Human Rights Watch interview with anonymous, anesthesiologist, Thiès Regional Hospital, Thiès, December 12, 2012.

Healthcare workers and patients also told us that in Senegalese culture, pain is something to be borne, not something to complain about. As one nurse put it, “[w]e can die of pain, but we cannot cry or show a face that we are feeling bad.”²¹⁵ One patient with breast cancer told Human Rights Watch that she had severe chest and shoulder pain that prevented her from sleeping for more than a year.²¹⁶ She said that she would have liked to have pain medication because, “if I had it, I would have been able to sleep, but I was not able to sleep at all.”²¹⁷ She never told her doctor about this pain because “the doctor never asked.”²¹⁸

In some cultural contexts in Senegal, expressing pain is widely seen as a sign of weakness, which makes it all the more important that healthcare workers routinely ask about pain and proactively evaluate it—otherwise patients will suffer. The case of Mouhammad Ndiasse underscores the importance of proper pain evaluation after pain medications have been prescribed. Mouhammad Ndiasse, a 13-year-old cancer patient, told Human Rights Watch he was receiving paracetamol, a weak analgesic, for pain caused by tumors in his neck. When asked whether they were effective, he answered, “yes.”²¹⁹ However, upon further inquiry, he and his mother told us the medication controlled the pain only for about one hour; he had to wake up three or four times during the night to retake it, and suffered from intermittent pain throughout the day.²²⁰ One patient, Serigne was in need of a higher level medication, but healthcare providers had not adequately or continually evaluated his pain.

Poor Evaluation and Treatment of Pain in Children

Misconceptions of morphine use are particularly complicated in pediatrics. Some healthcare providers erroneously equate palliative care with “giving up” on a child’s life, and may hesitate to give children any opiate pain relief. As a result, many children with pain may end up being treated inadequately. Training in evaluating pain in children is particularly important as younger children might not be able to express whether or not they are suffering. Human Rights Watch interviewed some parents of pediatric patients who recounted that their children had not been given pain medications at all.²²¹

²¹⁵ Human Rights Watch interview with Madické Gaye, December 4, 2012.

²¹⁶ Human Rights Watch interview with Assumption Mandoza, patient, Dantec Hospital Joliot Curie, Dakar, December 3, 2012.

²¹⁷ Ibid.

²¹⁸ Ibid.

²¹⁹ Human Rights Watch interview with Adama Gueye, mother of patient, Dantec Hospital Joliot Curie, Dakar, November 29, 2012.

²²⁰ Ibid.

²²¹ Human Rights Watch interviews with parents of pediatric patients, Dantec Hospital Pediatric Oncology Ward, November and December 2012.

WHO has expressed concern that, “[a]lthough the means and knowledge to relieve pain exists, children’s pain is often not recognized, is ignored or even denied.”²²² The WHO Guideline on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses emphasizes that, “[a]ll patients with pain, including children, should be treated, irrespective of whether or not the underlying cause can be identified. Inability to establish an underlying cause should not be a reason to conclude that the pain is fabricated.”²²³

The Guidelines recommend that the pain medications be given at regular intervals, not just when the child is in pain, and that oral medications be used whenever possible, and that the dosage and any auxiliary medications be adapted to the specific needs of the individual child.²²⁴ As long as the pain is not fully relieved, dosage should be increased no more than 50 percent per 24 hours.²²⁵

Drug Availability

The 1961 Single Convention on Narcotic Drugs created an international system to regulate supply and demand of controlled substances, which is monitored and enforced by the International Narcotics Control Board (INCB). National drug control agencies are responsible for communicating with the INCB about medical drug needs, imports and exports, and regulating all domestic transactions. Governments have exclusive control over the domestic supply of controlled substances. Thus, unlike medications which can be produced or imported freely, opiate analgesics will not be legally available unless the government ensures adequate supply and distribution.

In the context of the war on drugs, many countries, including Senegal, focus only on preventing illegal drug use, and neglect the obligation to ensure drug availability for medical purposes. The INCB has explicitly stated that “an efficient national drug control regime must involve not only a programme to prevent illicit trafficking and diversion but also a programme to ensure the adequate availability of narcotic drugs for medical and scientific purposes.”²²⁶

²²² WHO, “Persisting Pain in Children,” 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_%20Policy%20Brochure.pdf (accessed August 5, 2013) p. 4.

²²³ *Ibid.*

²²⁴ *Ibid.*, p. 11.

²²⁵ *Ibid.*, p. 11.

²²⁶ INCB, *Availability of Opiates for Medical Needs: Report of the International Narcotics Control Board for 1995* (New York: United Nations, 1995) p. 14.

Additionally, the INCB has said, “governments that have not done so should determine whether there are undue restrictions in national narcotics laws, regulations, or administrative policies that impede prescribing, dispensing or needed medical treatment of patients...[and] make the necessary adjustments.”²²⁷

In May 2013, the African Union (AU) adopted the African Common Position Paper on Controlled Substances and Access to Pain Management Drugs, which supports the INCB recommendations and urges member states to ensure an effective supply system of opiate medications and amend undue legal and regulatory restrictions on their availability. The Paper also calls on member states to promote comprehensive curricula on rational use of controlled medications in relevant educational and healthcare institutes and facilities.²²⁸

National drug availability programs must be capable of ensuring that adequate amounts of controlled medicines are available at all times; that an effective system of distribution is in place; that a sufficient number of pharmacies and health facilities stock them; that healthcare workers can prescribe these medications without unnecessary bureaucratic difficulties; and that patients around the country can reasonably gain access to them.²²⁹ As the World Health Organization has noted, good communication between health workers and drug regulators is crucial to meet these goals.²³⁰ To guarantee an effective distribution system, governments must ensure that a sufficient number of pharmacies are licensed to handle morphine and that procedures for procuring, stocking and dispensing it are workable.

Challenges with the Supply and Distribution of Opioid Analgesics

Senegal’s Quota for Opioid Analgesics

Countries submit estimates of their annual need for controlled medications to INCB, which then approves a quota for each country. Obtaining an appropriate quota is the first step toward ensuring the adequate availability of opioid analgesics. Many countries, however,

²²⁷ Ibid.

²²⁸ African Union, “African Common Position on Controlled Substances and Access to Pain Management Drugs,” October 2012, 5th Session of the AU Conference of Ministers of Drug Control, <http://www.carmma.org/sites/default/files/PDF-uploads/African%20Common%20Position%20on%20Controlled%20Substances%20and%20Access%20to%20Pain%20Mgt%20Drugs%20-%20English.pdf> (accessed June 25, 2013).

²²⁹ WHO, “Ensuring Balance in National Policies on Controlled Substances,” 2011, http://www.who.int/medicines/areas/quality_safety/GLs_Ens_Balance_NOCP_Col_EN_sanend.pdf (accessed August 6, 2013).

²³⁰ WHO, “Cancer Pain Relief: With a Guide to Opioid Availability,” 1996, <http://whqlibdoc.who.int/publications/9241544821.pdf> (accessed August 5, 2013), p. 5.

submit estimates that are not based on assessment of population need but on past consumption, which tends to vastly understate the actual medical requirement. The Head of Narcotics at the Directorate of Pharmacies and Medicines (DPM) told Human Rights Watch that sometimes Senegal reaches its quota during the year and has to request a supplemental quota from the INCB.²³¹ In such cases, morphine shortages are likely to occur as orders cannot be placed until that request is made and approved.

According to Dr. Daouda Diop, the Head of Technical Services and Operations at the National Pharmacy, Senegal has been using approximately the same quota since the 1960s.²³² To make estimates, the DPM sends inquiries to healthcare facilities concerning morphine usage.²³³ However, few facilities respond, thus the DPM ends up using what it has in previous years.²³⁴ As a result, for 2013, Senegal estimated it would need 1,180 grams of morphine,²³⁵ an amount that would suffice for about 194 patients with advanced cancer or HIV/AIDS.²³⁶ Given that morphine is also used to relieve post-surgical pain and in various other medical procedures, the actual number of palliative care patients that can be treated with that quota is far smaller.²³⁷ When approximately 5,100 Senegalese die each year from cancer²³⁸ and 1,600 from AIDS,²³⁹ and thousands more need palliative care for other illnesses, this quota is a tiny fraction of the actual need.

The INCB has repeatedly reminded countries of their obligation to submit estimates based upon medical requirement, and has encouraged all countries to review their methods for

²³¹ Human Rights Watch interview with Rokhaya Ndiaye Kandé, former head of narcotics, Direction de la Pharmacie et des Laboratoires, Dakar, December 7, 2012.

²³² Human Rights Watch interview with Daouda Diop, Head of Technical Services and Operations, PNA, Dakar, July 8, 2013.

²³³ Human Rights Watch interview with Rokhaya Ndiaye Kandé, December 7, 2012.

²³⁴ Human Rights Watch interview with Daouda Diop, July 8, 2013.

²³⁵ INCB, "Estimated World Requirements of Narcotic Drugs in Grams for 2013," 2013, <http://www.incb.org/documents/Narcotic-Drugs/Status-of-Estimates/2013/EstMay13.pdf> (accessed July 14, 2013).

²³⁶ Kathleen M. Foley, et al., "Pain Control for People with Cancer and AIDS," estimates that the average terminal cancer or AIDS patient who suffers from severe pain will need 60 to 75mg of morphine per day for an average of about 90 days. Senegal's consumption of morphine is approximately 1 kilogram, as reported by the International Narcotics Control Board in their technical report, available at: http://www.incb.org/documents/Narcotic-Drugs/Technical-Publications/2012/NDR_2012_Part4_Tables_EFS.pdf (accessed June 11, 2013).

²³⁷ Under the UN drug conventions, countries can request additional quota from INCB if the requested quota turns out to be insufficient. But countries that have poor systems for estimating their need are unlikely to submit supplementary requests.

²³⁸ As Senegal does not have a cancer registry, these figures are projections that are not based on statistics reported from the country itself. WHO International Agency for Research on Cancer, Globocan 2008, <http://globocan.iarc.fr/factsheet.asp> (accessed April 25, 2013).

²³⁹ UNAIDS, "Senegal," 2012, <http://www.unaids.org/en/regionscountries/countries/senegal/> (accessed July 11, 2013).

preparing estimates to ensure that they accurately reflect the actual requirement.²⁴⁰ To help countries fulfill this obligation, the INCB and WHO recently issued a Guide on Estimating Requirements for Substances under International Control.²⁴¹

The State Supply and Distribution System

Senegal has a central, state-run agency called the Pharmacie Nationale D'Approvisionnement (PNA), which procures medications that are on the country's essential medicines list and distributes them through a network of regional affiliates, known as Pharmacies Regional D'Approvisionnement (PRA). Public healthcare facilities can then order these medications at subsidized prices. In theory, this can be an effective vehicle for ensuring the availability of opioid analgesics throughout the country, but our research has found that it has not operated well for opiates for a variety of reasons.²⁴²

First, as noted above, Senegal's essential medicines list did not include oral morphine or weak opioid analgesics until the changes introduced in 2013. Private pharmacies sold weak opioids, but only hospitals could import morphine. The importation process is highly complex (see "Private Importation of Oral Morphine: A Complicated Process," Exploring the Causes of the Palliative Care Gap), so few hospitals actually did import them. Without the PNA, prices for these medications are more expensive because individual facilities do not order in bulk, and medicines from private pharmacies and suppliers are not subsidized. The Head of Importation at the PNA estimates that oral morphine will be stocked by the end of the year, which will be a great improvement.²⁴³ However, the list still does not have liquid oral morphine, and restricts dispensation of all morphine to regional and national hospitals. To improve palliative care access for children, and for people who live in rural areas, the government must include morphine syrup on the essential medicines list and allow district level health facilities to dispense opiate medications.

²⁴⁰ INCB, *Availability of Opiates for Medical Needs: Report of the International Narcotics Control Board for 1995*, p. 8.

²⁴¹ INCB and WHO, "Guide on Estimating Requirements for Substances under International Control," 2012, http://www.incb.org/documents/Narcotic-Drugs/Guidelines/estimating_requirements/NAR_Guide_on_Estimating_EN_Ebook.pdf (accessed July 15, 2013).

²⁴² We did not investigate in detail how well this supply system works for other, non-controlled medications. Healthcare workers indicated that they have not had problems with the supply of medications like paracetamol but that there sometimes are interruptions in the supply antibiotics of antibiotics.

²⁴³ Human Right Watch interview with Palaity Gning, Director of Importation, PNA, July 8, 2013.

Secondly, we found even with medications that were on the 2008 list of essential medicines, like injectable morphine and buprenorphine (locally known as Temgesic), the PNA did not have a constant supply. During our research in December 2012, the PNA has run out of injectable morphine and was in the process of ordering it.²⁴⁴ Additionally, there was a country wide shortage of Temgesic that had lasted over six months.²⁴⁵ One official at the PNA told Human Rights Watch that the PNA had not stocked Temgesic since 2008.²⁴⁶ While injectable morphine was restocked in about two weeks, officials at the PNA and DPM were unsure of the reasons for the Temgesic shortage, and Temgesic remained unavailable.²⁴⁷

Thirdly, we found that injectable morphine was never distributed to any of the PRAs outside Dakar.²⁴⁸ When Human Rights Watch asked officials at the DPM and PNA about the lack of distribution, they explained that no facilities outside of Dakar ask for morphine. The director of the PRA of Ziguinchor said, “There is no demand for morphine here. I only order the need of the region.”²⁴⁹ Yet, when Human Rights Watch interviewed doctors in Podor, Thiès and Ziguinchor, several said they wanted to use morphine, but when they asked for it, their pharmacies or local PRA said it was unavailable. An anesthesiologist at Thiès Regional Hospital, who has worked there since 2002, told us, “Each year, we ask [the PRA] for morphine...we have asked, and asked, and asked, and we still do not have it.”²⁵⁰ The head pharmacist at Thiès Regional Hospital said she wants to order morphine, but when she wrote to the DPM requesting authorization to stock it, she received no response. The pharmacist at Ndioum Regional Hospital tried to place an order for morphine once, but there was a shortage.²⁵¹

Several other doctors told Human Rights Watch that they would like to use morphine for patients, but never *asked* for it because they assumed it was unavailable. A surgeon in Thiès said that since morphine is not listed in the PRA’s catalogue of medicines, he assumes that it cannot be procured, therefore he has never asked for it. Similarly, a doctor

²⁴⁴ Human Rights Watch interview with Lamtoro Seck, Director of Programs, PNA, December 13, 2012.

²⁴⁵ Human Rights Watch interviews with private pharmacists, and Director of Laborex’s Senegal Office (supplier of Temgesic), Dakar, December 2012.

²⁴⁶ Human Rights Watch interview with Lamtoro Seck, December 13, 2012.

²⁴⁷ Ibid., and Rokhaya Ndiaye Kandé, December 13, 2012.

²⁴⁸ Human Rights Watch interview with Thyandoum Niang, head of distribution, Pharmacie National D’Approvisionnement, December 14, 2012.

²⁴⁹ Human Rights Watch interview with Mariama Sambou, Director, Pharmacie Regional D’Approvisionnement of Ziguinchor, Ziguinchor, December 5, 2012.

²⁵⁰ Human Rights Watch interview with Françoise Ndiaye, anesthesiologist, Thiès Regional Hospital, Thiès, December 12, 2012.

²⁵¹ Human Rights Watch interview with Mamadou Sakidé, head pharmacist, Ndioum Regional Hospital, Ndioum, November 22, 2012.

at Zingunchor’s Centre de Santé said, “What is available is available, what is not is not.” Doctors work without morphine because it is unavailable, and because they work without it, government officials assume that they do not need to use it.

Procurement Authorization

Prior to procuring opioid analgesics, healthcare institutions must obtain authorization from the Direction de la Pharmacie et des Médicaments (DPM). While this step is not necessarily a barrier to drug availability, there appeared to be confusion over what institutions can obtain such authorization and on what basis it is granted or denied.

Officials at the DPM told Human Rights Watch that there is no written regulation that sets out the authorization process, but several officials²⁵² and head pharmacists²⁵³ described it as follows. First, the head pharmacist of the hospital submits a written request for authorization to the DPM, specifying which narcotic and in what amount the hospital needs. Rokhaya Ndiaye Kandé, the Director of Narcotics at the DPM, told Human Rights Watch that her department reviews the request to determine whether there is “good justification” and examines the healthcare institution’s existing stock to ensure that it does not end up with “excessive” supply.²⁵⁴ If the DPM considers the request reasonable, authorization is granted and the institution can proceed with procurement from the PNA, PRA or a private supplier.²⁵⁵ Kandé told Human Rights Watch that denial of authorization is rare.²⁵⁶

Without clear written regulations, there is confusion as to who can stock morphine and how the DPM determines whether there is “good justification.” Kandé said that any hospital—but not a centre de santé or lower level facility—can apply.²⁵⁷ According to Kandé, frequent morphine shortages occur because hospitals do not understand the authorization process and do not manage opiate supply. If the morphine quota runs out, Kandé must arrange for a supplement with the INCB; she is unsure of the exact length of time this

²⁵² Human Rights Watch interview with Papasaliou Diop, Rokhaya Ndiaye Kandé, Annette Seck, Director of the PNA, Mariama Sambou, November and December 2012.

²⁵³ Human Rights Watch interviews Mamadou Sakide, Babakar Diop, head pharmacist of Grand Yoff Hospital, Mamadou Sakho, head pharmacist of Principal Hospital, Anta Sarr, head pharmacist of Thiès Regional Hospital, Babakar Faye, head pharmacist of Dantec Hospital, Al Fousseynou Samb, adjunct head pharmacist of Dantec Hospital, and Ngor Diagne, head pharmacist of Zingunchor regional hospital, Dakar, Thiès, Ndioum and Zingunchor, November and December 2012.

²⁵⁴ Human Rights Watch interview with Rokhaya Ndiaye Kandé, December 7, 2012.

²⁵⁵ Ibid.

²⁵⁶ Ibid.

²⁵⁷ Ibid.

process takes, but assured us that it takes “a very long time.”²⁵⁸ For opiates that are not on the list of essential medicines, the entire procurement process takes several months, and errors cause additional delays.

The head pharmacists interviewed said they usually begin this ordering process about three to four months before they expect stock to run out.²⁵⁹ According to them, lack of flexibility in the authorization process exacerbates shortages.²⁶⁰ For example, the central pharmacy at Dantec Hospital needed to order more oral morphine in September. They applied for and received authorization from the DPM, but when they proceeded with the order, they encountered difficulties paying the supplier.²⁶¹ By the time Dantec obtained the funds to pay for the medication, the authorization had expired.²⁶² The DPM initially refused to grant Dantec a new authorization form until the expired one, which had already been sent abroad to the supplier, was returned.²⁶³ After much convincing, the DPM finally consented to issuing a new authorization, but during that delay patients suffered.²⁶⁴

Rules for Handling, Prescribing and Dispensing of Opioid Analgesics

Under international law, countries must regulate the handling, prescribing and dispensing of strong opioid analgesics. The 1961 Single Convention on Narcotic Drugs lays out three minimum criteria that countries must observe in developing national regulations regarding the handling of opioids:²⁶⁵

- Individuals must be authorized to dispense opioids by their professional license to practice, or be specially licensed to do so;
- Movement of opioids may occur only between institutions or individuals so authorized under national law;
- A medical prescription is required before opioids may be dispensed to a patient.

²⁵⁸ Ibid.

²⁵⁹ Human Rights Watch interview with Babakar Faye and Al Fousseynou Samb, pharmacists, Dantec Hospital Central Pharmacy, December 3, 2012.

²⁶⁰ Ibid.

²⁶¹ Ibid.

²⁶² Ibid., Authorizations expire three months from date of issue.

²⁶³ Ibid.

²⁶⁴ Ibid.

²⁶⁵ 1961 Single Convention on Narcotic Drugs, Article 30(2bii), http://www.unodc.org/pdf/convention_1961_en.pdf (accessed August 5, 2013).

Governments may, under the Convention, impose additional requirements if deemed necessary, such as requiring that all prescription be written on official forms or authorized professional associations.²⁶⁶ However, WHO has emphasized that these requirements must be balanced with the obligation to ensure medical access to opiates,²⁶⁷ and any regulations that unnecessarily impede access will be inconsistent with both the UN drug conventions and the right to health. In 2011, WHO published a guideline, *Ensuring Balance in National Policies on Controlled Substances*, to help policy makers develop a “practical system.”²⁶⁸

Special Prescription Form

Senegalese regulations require doctors to write prescriptions for strong opioid analgesics on special prescription pads.²⁶⁹ These pads must be obtained from a hospital and carry the name of the doctor and a unique number.²⁷⁰ While the UN 1961 convention specifically allows countries to require their use, special prescription pads are often a significant barrier to the prescription of strong opioid analgesics because they limit the number of people who can prescribe them. In Senegal, only doctors can prescribe morphine. However, because the prescription pads are only dispensed from hospitals that stock morphine, doctors who are not employed by such hospitals will be unable to obtain the pads. Even in certain hospitals, the number of doctors who are given these pads is limited. According to the head pharmacist at Principal Hospital, only two doctors in the entire hospital are authorized to prescribe morphine.²⁷¹

In rural areas, where the ratio of doctor to patient is said to be low, it is almost impossible for patients to find someone with the authority to prescribe morphine to relieve their pain. WHO recommends that the competence to prescribe controlled medicines, including strong opioids, not be restricted to a small number of medical specialties, and that they should be available through a sufficiently dense network of pharmacies or other distribution points.²⁷²

²⁶⁶ Ibid.

²⁶⁷ WHO, “Cancer Pain Relief: With a Guide to Opioid Availability,” 1996, <http://whqlibdoc.who.int/publications/9241544821.pdf> (accessed August 5, 2013), p. 9.

²⁶⁸ WHO, “Ensuring Balance in National Policies on Controlled Substances,” 2011, http://www.unodc.org/docs/treatment/Pain/WHO_encuring_balance_controlled_substances.pdf (accessed July 17, 2013).

²⁶⁹ Human Rights Watch interview with Ahmadou Dem, Claude Moriera, Abdoul Kassé, and Oumar Ba, November 2012.

²⁷⁰ Ibid.

²⁷¹ Human Rights Watch interview with Mamadou Sakho, Adjunct Head Pharmacist, Principal Hospital Pharmacy, Dakar, November 29, 2012.

²⁷² WHO, “WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,” 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf (accessed June 27, 2013), p. 6.

Several other countries have changed their regulations to allow nurses to prescribe oral morphine, greatly expanding the range of distribution of these medicines.

Time Limit on Prescriptions

Under Senegal's law on drugs, doctors cannot prescribe more than a seven-day supply of any substance under Table II, plants and substances that have a high risk of abuse.²⁷³ Because morphine is included under Table II, doctors can only prescribe one week's worth of the medication per prescription.²⁷⁴ While the law explicitly permits the Minister of Health to extend this time limit by ministerial decree to a maximum of 60 days, no such decree had been issued for morphine.²⁷⁵ Since prescriptions for table II substances must be filled within seven days of the date issued,²⁷⁶ doctors can give patients one refill, which cannot be filled at the same time as the initial prescription.²⁷⁷ Thus, patients who need strong opiates, or any table II medication, must return to their doctor at least every two weeks to get new prescriptions, and go to the pharmacy every week to fill prescriptions.²⁷⁸ Since morphine is only available in Dakar, patients who live outside the capital must travel on a weekly basis; for many, the journey is long and expensive. Furthermore, these patients must pay a consultation fee every two weeks to see their doctor and pick up prescriptions. When they are too weak to travel any longer, they may send a relative to Dakar, relocate to Dakar, or suffer at home.

While there are good reasons, including preventing diversion, for certain limitations on the length of time medications can be dispensed, Senegal's time restriction is excessively burdensome, and more restrictive than the one imposed by most other African countries. A survey by Nathan Cherny of the European Society for Medical Oncology on availability of opioid medications in 23 African countries found that only

²⁷³ Première Partie Classification et Réglementation de la Culture, de la Production, de la Fabrication et du Commerce Licites des Stupéfiants, Substances Psychotropes et Précurseurs, République du Senegal, November 11, 1997, arts.2 and 58.

²⁷⁴ Ibid.

²⁷⁵ Ibid.,art. 59. Article 59 states, "the drugs in Table II, appointed by decree of the Minister of Health, may be prescribed for a period exceeding seven days to a maximum of sixty days" (les médicaments du Tableau II désignés par arrêté du Ministre chargé de la Santé, peuvent être prescrits pour une période supérieure à sept jours sans pouvoir excéder soixante jours).

²⁷⁶ Ibid., art. 60.

²⁷⁷ Human Rights Watch interview with Abdoul Kassé, November 13, 2012, and Zal Baldé, pulmonologist, Grand Yoff Hospital, Dakar, November 20, 2012 and Oumar Ba, November 26, 2012.

²⁷⁸ Ibid.

five had a prescription limit of seven days or less; five had a limit of ten to fifteen days; and eleven had a limit of twenty-eight days or more.²⁷⁹

In recent years, there has been a global trend to increase the length of time a prescription for oral morphine can cover, with many countries settling on about a month. Some countries that changed their limits in recent years include Romania (from 3 to 30 days), France (from 7 to 28 days), Mexico (from 5 to 30 days), Peru (from 1 to 14 days), and Colombia (from 10 to 30 days).²⁸⁰

The Lack of a Network of Pharmacies with Oral Morphine

As of July 2013, Dantec Hospital's Central Pharmacy is the only pharmacy in all of Senegal that sells oral morphine to the public. While Grand Yoff Hospital and Principal Hospital also have oral morphine, the supply is limited to their inpatients only.²⁸¹ The head pharmacist of Dantec told Human Rights Watch that patients come to his pharmacy from various other hospitals and private clinics, making it difficult to estimate needs and sometimes leading to shortages.²⁸²

There used to be another pharmacy in Dakar that sold oral morphine to the public, a private pharmacy called Pharmacie Guigone. Though Guigone had been selling oral morphine for decades, a ministerial decree in early 2012 forbid them from continuing sales.²⁸³ According to the Director of Narcotics at the Direction de la Pharmacies et des Medicaments, Guigone's sale of the pills was in violation of Senegalese law because the only hospitals are allowed to stock morphine.²⁸⁴ With Guigone unable to sell oral morphine anymore, patients have become even more reliant on Dantec Hospital. Expanding distribution to private pharmacies would establish a buffer against shortages and increase the accessibility of opiate medicines.

²⁷⁹ Nathan I Cherny, "The International Collaborative Project to Evaluate the Availability and Accessibility of Opioids for the Management of Cancer Pain in Africa, Asia, Latin America and Middle East," European Society for Medical Oncology, undated, <http://www.esmo.org/content/download/8638/175562/file/ESMO-Opioid-Survey-slides-AFRICA.pdf> (accessed August 5, 2013).

²⁸⁰ Vanessa Adams, *Access to Pain Relief: an Essential Human Right* (London: Help the Hospices, 2007), p. 39.

²⁸¹ Human Rights Watch interview with Mamadou Sakho, November 29, 2012 and Babakar Diop, December 4, 2012.

²⁸² Human Rights Watch interview with Babakar Faye and Al Fousseynou Samb, December 3, 2012.

²⁸³ Human Rights Watch interview with pharmacists at Guigone Pharmacy, Guigone Pharmacy, Dakar, December 10, 2012.

²⁸⁴ Human Rights Watch interview with Rokhaya Ndiaye Kandé, December 13, 2012.

Private Importation of Oral Morphine: A Complicated Process

Though the government added morphine pills to the 2012 list of essential medicines, at time of this writing the PNA still has not begun procuring morphine pills. Additionally, liquid morphine still has not been added. As a result, hospitals must import all oral morphine themselves, a process that is extremely complicated due to government anti-corruption regulations.

Under Senegalese law, public institutions may buy medications or other goods from a private supplier only after going through a competitive bidding process.²⁸⁵ If the funds for the purchase come from the government, only Senegalese companies are permitted to bid; any international supplier wishing to participate must do so through a domestic partner.²⁸⁶ The public institution must take the lowest bid.²⁸⁷ The government enacted this requirement to prevent corruption and promote efficiency and transparency, but since hospitals order a small quantity and the profit margin on morphine is low, no suppliers bid. Only three hospitals managed to procure oral morphine, and had to go through great difficulty to do so.²⁸⁸

For morphine pills, pharmacists at Dantec, Principal, and Grand Yoff told Human Rights Watch they had launched competitive bidding processes but had received no bids.²⁸⁹ Mamadou Sahko, the adjunct head pharmacist at Principal Hospital, for example, said that no supplier had responded to their calls for bids for morphine pills in the past two years.²⁹⁰ However, a direct purchase from a private supplier is permitted only if the bidding process fails

²⁸⁵ Recueil de Textes Juridiques sur les Marchés Public, 2011, art. 60 and Loi no. 2006-16 modifiant la loi no. 65-61 du 19 juillet 1965 portant Code des Obligations de l'Administration, 2006, art. 26.

²⁸⁶ Loi no. 2006-16 modifiant la loi n° 65-61 du 19 juillet 1965 portant Code des Obligations de l'Administration, art. 28.

²⁸⁷ Code de Marchés Public, Décret No 2007-545, République du Sénégal, April 25, 2007, article 6. See also Loi no. 2006-16 modifiant la loi no. 65-61 du 19 juillet 1965 portant Code des Obligations de l'Administration, article 26, "L'appel d'offres ouvert constitue le mode de passation des marchés auquel les autorités contractantes doivent recourir par principe. Il ne peut être dérogé à ce principe que dans les conditions stipulées par le code des marchés publics."

²⁸⁸ Human Rights Watch interview with Idrissa Ba, Court du Marché Public, Dakar, December 14, 2012.

²⁸⁹ Human Rights Watch interview with Babakar Faye and Al Fousseynou Samb, December 3, 2012 and Babakar Fall, Representative, Bristol-Myers Squibb, Dakar, December 11, 2012.

²⁹⁰ Human Rights Watch interview with Mamadou Sakho, November 29, 2012.

at least twice, and after the Ministry of Markets examines the reasons for the failure.²⁹¹After that, the public institution must request bids directly from companies that are potentially interested.²⁹² If that too fails, then the institution can order directly from the supplier.²⁹³ At the time of our research, only Dantec Hospital and Grand Yoff have morphine pills.

For morphine syrup, Dantec Hospital, Grand Yoff Hospital, and Principal Hospital managed to import morphine powder, which they dilute with syrup to make liquid morphine. To obtain the powder however, Dantec's pharmacists said they had to beg Val D'Afrique, a Senegalese company, to act as an intermediary to purchase the powder from an international company.²⁹⁴ The representative of Val D'Afrique told Human Rights Watch that they wait for the hospital to place an order before ordering from an international supplier; since the powder is not profitable, they do not keep it in stock.²⁹⁵ As a result, shortages cannot be addressed quickly.

²⁹¹ Human Rights Watch interview with Idrissa Ba, December 14, 2012.

²⁹² Ibid.

²⁹³ Ibid.

²⁹⁴ Human Rights Watch interview with Babakar Faye and Al Fousseynou Samb, December 3, 2012

²⁹⁵ Human Rights Watch phone interview with Val D'Afrique Representative, Dakar, December 11, 2012.

IV. Senegal's Obligation to Improve Palliative Care

National Law

Article 8 of Senegal's constitution guarantees the right to health to all its citizens, stating:

The Republic of Senegal guarantees all citizens basic freedoms, the economic and social rights and collective rights as follows...the right to health...The only limitation in principle to the exercise of a freedom guaranteed by the Constitution is that this exercise must respect the freedom of others and do not create harm to others or disturb public order.²⁹⁶

Article 17 further states:

The State and local public office have a duty to ensure the health and welfare of the family, and in particular persons with disabilities and the elderly. Rural women have the right to access to health and well-being.²⁹⁷

The constitution does not define the exact scope or content of the right to health, but Health is a fundamental human right enshrined in numerous international human rights instruments, several of which Senegal is party to.

The Right to Health

The International Covenant on Economic Social and Cultural Rights (ICESCR)'s article 12 specifies that everyone has a right "to the enjoyment of the highest attainable standard of physical and mental health."²⁹⁸ The Committee on Economic, Social and Cultural Rights, the body charged with monitoring compliance with the ICESCR, has held that states must make available in sufficient quantity "functioning public health and health-care facilities, goods and services, as well as programmes," and that these services must be accessible. Article 16 of the African Charter on Human and Peoples' Rights

²⁹⁶ Constitution de la Republique du Senegal, January 22, 2001, <http://www.gouv.sn/IMG/pdf/Constitution.pdf> (accessed June 11, 2013), art. 8.

²⁹⁷ *Ibid.*, art. 17.

²⁹⁸ International Covenant on Economic Social and Cultural Rights, adopted by General Assembly resolution 2200A (XXI) of 16 December 1966, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx> (accessed August 6, 2013), art. 12.

(ACHPR) states that, “every individual shall have the right to enjoy the best attainable state of physical and mental health...State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”²⁹⁹

The Convention on the Rights of the Child (CRC)’s article 24 states, “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health...States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.” Under international law, children have the right to access health care without discrimination on the basis of age or health status, among other grounds. The CRC, the ACHPR and the African Charter on the Rights and Welfare of the Child all protect children from discrimination on various grounds, including “other status.”³⁰⁰ Bodies responsible for interpreting international conventions have stated that “other status” includes both age and health status.³⁰¹ Therefore, children cannot be arbitrarily excluded from palliative care services, and reasonable steps must be taken to ensure that palliative care appropriate for children of all ages is available, and at least as accessible as services for adults.

Because states have different levels of resources, international law does not mandate the kind of health care to be provided. The right to health is considered a right of "progressive realization." By becoming party to the international agreements, a state agrees "to take steps...to the maximum of its available resources" to achieve the full realization of the right to health. In other words, high-income countries will generally have to provide healthcare services at a higher level than those with limited resources. But all countries will be expected to take concrete steps toward increased services, and regression in the provision of health services will, in most cases, constitute a violation of the right to health.

²⁹⁹ African Charter on Human and Peoples' Rights, January 25, 2005, <http://www.achpr.org/instruments/achpr/#a16> (accessed August 6, 2013), art. 16.

³⁰⁰ The Children Act, sec. 5; ICESCR, art. 2; CRC, art. 2; African Charter on Human and Peoples' Rights, art. 2; African Charter on the Rights and Welfare of the Child; art. 3.

³⁰¹ UN Committee on Economic, Social and Cultural Rights, “Non-discrimination in Economic, Social and Cultural Rights (art.2, para. 2, of the International Covenant on Economic, Social and Cultural Rights),” General Comment No. 20, U.N. Doc. E/C.12/GC/20 (2009), paras. 29, 33; UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, para. 18; UN Committee on the Rights of the Child, “Adolescent Health and Development in the Context of the Convention on the Rights of the Child,” General Comment No. 4, U.N. Doc. CRC/GC/2003/4 (2003), para. 6.

Notably, the United Nations Committee on Economic, Social and Cultural Rights has also held that there are certain core obligations that are so fundamental that states must fulfill them. While resource constraints may justify only partial fulfillment of some aspects of the right to health, the Committee has observed vis-à-vis the core obligations that "a State party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations..., which are non-derogable." The Committee has identified, among others, the following core obligations:

- To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;
- To ensure equitable distribution of all health facilities, goods and services;
- To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population.³⁰²

The Committee lists the obligation to provide appropriate training for health personnel as an "obligation of comparable priority."

Senegal ratified the ICESCR in 1978, the ACHPR in 1982, and the CRC in 1990.

Palliative Care and the Right to Health

Given that palliative care is an essential part of healthcare, the right to health requires that countries take steps to the maximum of their available resources to ensure that it is available. Indeed, the Committee on Economic, Social and Cultural Rights has called for "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity." A number of different state obligations flow from this:

³⁰² UN Committee on Economic, Social and Cultural Rights, "Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights," General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000), [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358boe2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358boe2c1256915005090be?Opendocument) (accessed May 11, 2006), para. 43. The Committee on Economic, Social and Cultural Rights is the UN body responsible for monitoring compliance with the International Covenant on Economic, Social and Cultural Rights.

- A negative obligation to refrain from enacting policies or undertaking actions that arbitrarily interfere with the provision or development of palliative care;
- A positive obligation to take reasonable steps to facilitate the development of palliative care; and
- A positive obligation to take reasonable steps to ensure the integration of palliative care into existing health services, both public and private, through the use of regulatory and other powers as well as funding streams.

No Interference with Palliative Care

The Committee on Economic, Social, and Cultural Rights has stipulated that the right to health requires states to “refrain from interfering directly or indirectly with the enjoyment of the right to health.”³⁰³ States may not deny or limit equal access for all persons, enforce discriminatory health policies, arbitrarily impede existing health services, or limit access to information about health.³⁰⁴ Applied to palliative care, this obligation means that states may not put in place drug control regulations that unnecessarily impede the availability and accessibility of essential palliative care medications, such as morphine and other opioid analgesics.

Facilitating the Development of Palliative Care

The right to health also includes an obligation to take positive measures that “enable and assist individuals and communities to enjoy the right to health.”³⁰⁵ Applied to palliative care, this means that states must take reasonable steps in each of the three areas the World Health Organization has identified as essential to the development of palliative care.³⁰⁶ As noted in chapter IV, these three prongs of WHO correspond closely with several core obligations under the right to health, which means that states cannot claim insufficient resources as justification for failing to take steps in these three areas.³⁰⁷

³⁰³ *Ibid.*, para 33.

³⁰⁴ *Ibid.*, para 33.

³⁰⁵ *Ibid.*, para 37.

³⁰⁶ WHO, “Cancer Pain Relief: With a Guide to Opioid Availability,” 1996, <http://whqlibdoc.who.int/publications/9241544821.pdf> (accessed August 5, 2013), p. 3.

³⁰⁷ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para 47.

Ensuring Age Appropriate Palliative Care for Children

The government should include a medical protocol on pain management for children in accordance with the WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses. The palliative care strategy should outline plans to create palliative care units with expertise in children's palliative care in district, provincial, and national hospitals, and ensure that existing services respond to the needs of children and their families, and raise awareness about the existence of these services.

Ensuring Integration of Palliative Care into Health Services

The right to health requires states to take the steps necessary for the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.”³⁰⁸ The Committee on Economic, Social and Cultural Rights has held that people are entitled to a “system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health,”³⁰⁹ including chronic or terminal illness.

The Committee has called for an integrated approach to the provision of different types of health services that includes elements of “preventive, curative and rehabilitative health treatment.”³¹⁰ It has also held that investments should not disproportionately favor expensive curative health services which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population.³¹¹ The same principle applies to palliative care services. WHO recommends that low- and middle-income countries focus on developing community-based palliative care services because they are inexpensive. Given the large percentage of cancer and other patients who require palliative care services, particularly in low- and middle-income countries, considerable urgency needs to be given to developing palliative care services for these patients.

Pain Treatment Medication and the Right to Health

As injectable and oral morphine are on the WHO List of Essential Medicines for adults and for children, countries have to provide these medications as part of their core obligations under the right to health, regardless of whether they have been included on

³⁰⁸ ICESCR, art. 12 (2).

³⁰⁹ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para 8.

³¹⁰ *Ibid.*, para 25.

³¹¹ *Ibid.*, para 19.

their domestic essential medicines lists.³¹² States must make sure these medicines are both available in adequate quantities and physically and financially accessible for those who need them.

In order to ensure availability and accessibility, states have, among others, the following obligations:

- Since the market for controlled medicines like morphine are completely in government hands, states must put in place an effective procurement and distribution system and create a legal and regulatory framework that enables healthcare providers in both the public and private sector to obtain, prescribe and dispense these medications. Any regulations that arbitrarily impede the procurement and dispensing of these medications will violate the right to health.
- States need to adopt and implement a strategy and plan of action for the roll out of pain treatment and palliative care services. Such strategy and plan of action should identify obstacles to improved services as well as steps to eliminate them.
- States should regularly measure progress made in ensuring availability and accessibility of pain relief medications.
- The requirement of physical accessibility means that these medications must be "within safe physical reach for all sections of the population, especially vulnerable or marginalized groups."³¹³ States must ensure that a sufficient number of healthcare providers or pharmacies stock and dispense morphine, and that an adequate number of healthcare workers are trained and authorized to prescribe these medications.

Financial accessibility means that, while the right to health does not require states to offer medications free of charge, they must be "affordable for all." In the words of the Committee:

Payment for health-care services...has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided,

³¹² WHO, "List of Essential Medicines," 2011, whqlibdoc.who.int/hq/2011/a95053_eng.pdf, and whqlibdoc.who.int/hq/2011/a95054_eng.pdf (accessed August 5, 2013) includes the following opioid analgesics: Codeine Tablet: 30 mg (phosphate); Morphine Injection: 10 mg (morphine hydrochloride or morphine sulfate) in 1-ml ampoule; Oral liquid: 10 mg (morphine hydrochloride or morphine sulfate)/5 ml., Tablet: 10 mg (morphine sulfate); Tablet (prolonged release): 10 mg; 30 mg; 60 mg (morphine sulfate).

³¹³ UN Committee on Economic, Social and Cultural Rights, General Comment 14, para. 12.

are affordable to all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

Countries have an obligation to progressively implement palliative care services, which, according to WHO, must have "priority status within public health and disease control programmes."³¹⁴ Countries must take all steps that are reasonable within available resources to execute the plan. Failure to attach adequate priority to developing palliative care will violate the right to health.

Pain Treatment and the Right to Be Free from Cruel, Inhuman and Degrading Treatment

The right to be free from torture, cruel, inhuman and degrading treatment or punishment is a fundamental human right that is recognized in numerous international human rights instruments.³¹⁵ Apart from prohibiting the use of torture, cruel, inhuman, and degrading treatment or punishment, the right also creates a positive obligation for states to protect persons in their jurisdiction from such treatment.³¹⁶

This obligation includes protecting people from unnecessary pain related to a health condition. As Manfred Nowak, the UN Special Rapporteur on Torture, Cruel, Inhuman and Degrading Treatment and Punishment wrote in a joint letter with the UN Special Rapporteur on the Right to Health to the Commission on Narcotic Drugs in December 2008:

³¹⁴ WHO, "National Cancer Control Programme: Policies and Managerial Guidelines", Second Edition, 2002, <http://www.who.int/cancer/media/en/408.pdf> (accessed August 5, 2013), p. 86.

³¹⁵ International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, art. 7 provides, "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment"; Universal Declaration of Human Rights (UDHR), adopted December 10, 1948, G.A. Res. 217A(III), U.N. Doc. A/810 at 71 (1948); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Convention against Torture), adopted December 10, 1984, G.A. Res. 39/46, annex, 39 U.N. GAOR Supp. (No. 51) at 197, U.N. Doc. A/39/51 (1984), entered into force June 26, 1987, article 16 provides that "Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity"; Inter-American Convention to Prevent and Punish Torture, O.A.S. Treaty Series No. 67, entered into force February 28, 1987; European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (ECPT), signed November 26, 1987, E.T.S. 126, entered into force February 1, 1989; African [Banjul] Charter on Human and Peoples' Rights, adopted June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), entered into force October 21, 1986.

³¹⁶ See for example the judgment of the European Court of Rights in *Z v United Kingdom* (2001) 34 EHRR 97.

Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation.³¹⁷

In a report to the Human Rights Council, Nowak later specified that, in his expert opinion, “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.”³¹⁸

Not every case where a person suffers from severe pain but has no access to appropriate treatment will constitute cruel, inhuman, or degrading treatment or punishment. Human Rights Watch believes that this will only be the case when the following conditions are met:

- The suffering is severe and meets the minimum threshold required under the prohibition against torture and cruel, inhuman, or degrading treatment or punishment;
- The state is, or should be, aware of the level and extent of the suffering;
- Treatment is available to remove or lessen the suffering but no appropriate treatment was offered; and
- The state has no reasonable justification for the lack of availability and accessibility of pain treatment.

In such cases, states will be liable for failing to protect a person from cruel, inhuman, or degrading treatment.

Senegal ratified the International Covenant on Civil and Political Rights in 1978, and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment in 1986.

³¹⁷ A copy of the letter is available at <http://www.ihra.net/Assets/1384/1/SpecialRapporteursLettertoCND012009.pdf> (accessed January 16, 2013).

³¹⁸ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, January 14, 2009, <http://daccessdds.un.org/doc/UNDOC/GEN/G09/103/12/PDF/G0910312.pdf?OpenElement> (accessed August 4, 2013), para. 72.

Recommendations

The introduction of palliative care in Senegal, at major hospitals as well as in the community, is urgently needed to prevent the gross and unnecessary suffering of tens of thousands of people throughout the country. As a signatory to various international human rights treaties and the UN drug conventions, the government has an obligation to play a central role in making this happen. It should work closely with the Association Senegalaise de Soins Palliatif, the World Health Organization, the African Palliative Care Association, and other partners to develop and implement a palliative care strategy that ensures patients in both cities and rural areas have access to basic palliative care services. In designing and implementing such strategy, the authorities in Senegal can draw on the experiences of countries like Uganda and Rwanda.

Based on our research, a national palliative care strategy should contain the following central components:

- **Integration of palliative care into services offered at national hospitals.** National hospitals, such as Dantec, Principal, Fann and Grand Yoff, attend to large numbers of patients with advanced chronic illnesses such as cancer, HIV, and late-stage renal, heart or lung disease. These hospitals, while often understaffed and overcrowded, have the capacity to integrate palliative care into their services at very low cost if they explicitly make symptom management a priority, offer palliative care training to staff, and ensure the availability of essential medications such as oral morphine. Such palliative care services must include children's palliative care and have staff trained in pediatric palliative care.
- **Provision of palliative care through primary health clinics.** Seventy percent of Senegal's population lives in rural areas and the majority of these people are poor.³¹⁹ Unless palliative care becomes available near their homes, these people will continue to die in horrific circumstances when they fall ill with cancer or other chronic illnesses. Basic palliative care services should be offered through health centers and posts, which are significantly more accessible to the population. This will require training nursing and other staff there in basic palliative care skills (pain assessment, treatment of mild to moderate pain, children's palliative care, etc.)

³¹⁹ The Peace Corps, "About Senegal," <http://www.pcsenegal.org/pages/93-about-senegal>.

and setting up referral systems for management of more complex symptoms that cannot be addressed properly at lower level facilities.

- **Palliative care training for all healthcare workers.** The lack of knowledge of palliative care is a key barrier to developing this health service. A strategy should present a clear vision for addressing the training needs of active doctors and nurses as well as for nursing and medical students in palliative care, including children's palliative care.
- **Ensuring the availability of palliative care drugs.** The provision of palliative care is impossible without opioid analgesics. A national strategy would need to present a clear plan for ensuring the uninterrupted supply of such medications and their distribution to all relevant hospitals and health facilities, including child-appropriate formulations. In particular, the strategy should task the Pharmacie Nationale d'Approvisionnement with procuring oral morphine tablets and syrup and their distribution to all regional affiliates and make it mandatory for all national and regional hospitals, as well as centre de santé, to stock oral morphine. A strategy should also aim to lift the seven-day restriction on prescribing of opioid analgesics and authorize nurses to prescribe oral opiates.

To the Senegalese Government

In the Area of Policy Development

- **Develop a national cancer control plan.** This plan should include a robust palliative care component, list detailed steps aimed at integrating palliative care into these strategies, and provide for specific and adequate allocations of resources for palliative care development. The plan should specifically address children's palliative care.
- **Incorporate palliative care in national HIV/AIDS plan.** The current plan should be amended to include a robust palliative care component, list detailed steps aimed at integrating palliative care into these strategies, and provide for specific and adequate allocations of resources for palliative care development.
- **Include liquid morphine in the essential medicines list.**
- **Increase the prescription period of opiates from seven days, and expand prescription authority to all doctors, as well as to nurses in rural areas.**

- **Expand the type of health facilities authorized to stock and dispense opioid analgesics.** Strong opioid analgesics, such as oral and injectable morphine, should be made available at least at the district level, at health centers (centre de santé). Weak opioids, such as tramadol, should be available at health posts (poste de santé). Allowing private pharmacies to sell oral opioid analgesics would also greatly expand access and protect against shortages.
- **Create community-based palliative care services, including for children.** The current system of rotating nurses with vehicles used to dispense treatment for malaria and vaccinations among rural villages can easily be expanded to include oral morphine medication.
- **Allow hospitals and healthcare facilities to have timely access to national and international suppliers.** The government should, in cooperation with the Ministry of Markets, develop guidelines to allow flexibility for hospitals, the PNA, and other public structures affiliated with the procurement of medicine to make direct purchases of medications from international and national vendors.

In the Area of Education

- **Introduce palliative care instruction into medical and nursing curricula.** Establish a clear standard for education in palliative care and pain treatment to ensure that all healthcare providers have at least basic training in the discipline. Healthcare providers who see large numbers of patients in need of palliative care should receive in-depth training and exposure to clinical practice. They also need to be trained in assessing and treating pain in children, providing psychosocial support for children and their families, and other aspects of children's palliative care.
- **Provide continued medical and nursing education.** Palliative care and pain management should be included in mandatory continued education programs for all general practitioners, oncologists, infectious disease doctors, anesthesiologists, geriatrists, and nurses.
- **Organize palliative care training sessions at regional hospitals.** Regional hospitals organize monthly meetings at which healthcare workers from the region gather. These meetings are ideal opportunities for discussing the importance of palliative care and strategies to begin implementing such services.

- **Develop training modules.** The Ministry of Health should develop training modules for doctors, nurses, social workers, counselors, and volunteers, in cooperation with the Senegalese Association for Palliative Care and other relevant palliative care groups.
- **Ensure that oral morphine and other opioid analgesics are provided to patients in their home through community-based (home-based) health services.**

In the Area of Drug Availability

- **Estimate the actual need and requirement for opioid analgesics.** Senegal's 2013 estimate for opioid analgesics was very low. Instead of estimating based on current usage, the government must estimate based on the number of people in the country afflicted with diseases that require pain management. The government should use the WHO-INCB guideline on estimates.
- **Ensure adequate and uninterrupted supply.** The Pharmacie Nationale d'Approvisionnement should ensure an adequate and uninterrupted supply of oral morphine and other opioid analgesics for all health facilities.
- **Ensure availability in regions.** All Pharmacies Regional d'Approvisionnement should be required to stock oral morphine and other opioid analgesics and distribute them to regional hospitals and other relevant health facilities, including at the district level.

To the International Community

To the International Narcotics Control Board

- Consistently report in the annual report on the availability of controlled substances for medical and scientific purposes in countries, including on specific barriers that impede such availability.
- Plan a fact-finding mission to Senegal, with availability of controlled substances for medical and scientific purposes as one area of focus. On such a mission, the INCB delegation should meet both with relevant government officials and representatives of palliative care organizations, such as the Senegalese Association for Palliative Care and any other leading palliative care groups.
- Establish regular contact with key palliative care leaders to ensure the INCB receives information on opioid availability barriers directly from healthcare providers.

- Offer technical support to Senegal in making its annual estimate for its requirement of opioid analgesics.
- Urge Senegal to submit data on consumption of morphine every year, as required by the 1961 Single Convention on Narcotic Drugs.

To the World Health Organization and UN Office on Drugs and Crime

- Raise concerns with the Senegalese government about the problems with availability and accessibility of controlled medications identified in this report.
- Urge the government to use the WHO tool for assessing drug policies to review its regulations and offer technical assistance.
- The WHO Access to Controlled Medications Programme should offer technical assistance to the Senegalese government on drug regulatory reform and educational barriers.
- Urge the government to implement resolution 53/4 of the Commission on Narcotic Drugs.
- Clarify that morphine powder is also an essential medicine; countries that have difficulty finding a supplier of morphine syrup can purchase morphine powder and healthcare workers can use it make morphine syrup.

To International Donors, in Particular the Global Fund against AIDS, Tuberculosis and Malaria, the US and EU Governments

- Ensure that palliative care and pain management are an integral part of any programs that are funded to provide care for people living with HIV and AIDS.
- Require that supported healthcare institutions obtain a license for morphine and other opioid analgesics and maintain an adequate stock of these medications.
- Financially support training of healthcare workers at hospitals and community health facilities on palliative care and pain management and provision of pain relief medications.
- Increase funding for the prevention and treatment of cancer and other non-communicable diseases.
- Fund programs for the psychosocial treatment of people afflicted by life-limiting chronic diseases, such as cancer and HIV.

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We are deeply grateful to the many palliative care patients in Senegal who, despite being gravely ill, agreed to be interviewed for this report. Without them and their relatives, this manuscript would not have been possible. We are committed to using this report to try to make sure that others who develop life-threatening illness—and pain and other symptoms associated with it—will not have to endure the suffering many of these patients faced.

We are also greatly indebted to the many palliative care advocates, doctors, nurses, pharmacists, social workers and volunteers in Senegal and elsewhere who helped us conduct our research, understand our findings, and write this report. Their commitment to serving people at the most vulnerable time of their lives is both humbling and inspiring.

ABANDONED IN AGONY

Cancer and the Struggle for Pain Treatment in Senegal

Non-communicable diseases, such as cancer, diabetes and heart disease, are responsible for 30 percent of all deaths in Senegal, and cancer alone kills more Senegalese than malaria, tuberculosis, and HIV/AIDS combined. In the coming decades, the prevalence of non-communicable illnesses in Senegal, as in Africa as a whole, is projected to increase significantly. That increase could bring an epidemic of pain: Over 70 percent of Senegalese cancer patients arrive in hospitals in advanced stages of illness, during which pain is intense and curative options are limited.

Abandoned in Agony: Cancer and the Struggle for Pain Treatment in Senegal highlights the need for urgent action to address palliative care in the country. The majority of cancer patients live and die in unbearable pain, even though there are cheap and effective methods to alleviate their suffering. Morphine, an essential medicine that is critical for adult and paediatric pain treatment, is unavailable outside of Dakar, the capital city. Even in Dakar, shortages are common. Overly stringent regulations on stocking and purchasing morphine make it difficult for hospitals to make it available to patients. Inflexible rules on morphine prescription make it virtually impossible for many Senegalese to get their medication.

Palliative care services are critical to minimizing suffering, and could be quickly, easily, and cheaply implemented even within the country's existing health infrastructure. It is a critical part of the fight against chronic and non-communicable diseases. Senegal can no longer ignore palliative care when so many people reach advanced stages of illness and experience severe pain. The Senegalese government has a human rights obligation to address the major causes of disease and suffering in the country, and ensure that the right to health is a reality in Senegal.



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During a morphine shortage, a cancer patient in Dakar clutches onto the railing of her hospital bed because she is in pain and the medication she needs is unavailable.