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ABANDONED IN AGONY

Cancer and the Struggle for Pain Treatment in Senegal

Summary and Key Recommendations



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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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 Nationale 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.

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.