Kenya

Needless Pain

Government Failure to Provide Palliative Care for Children in Kenya

HUMAN RIGHTS WATCH

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Printed in the United States of America
ISBN: 1-56432-668-3
Cover design by Rafael Jimenez

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SEPTEMBER 2010 **1-56432-668-3**

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Key Terms in Palliative Care and Pain Treatment

Palliative care: Health care 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 Kenya, 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 should be 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.

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 **dihydrocodeiene** (known in Kenya as **DF-118**).

Morphine: A strong opioid medicine, 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.

Basic pain medicines: Non-opioid pain medicines suitable for mild pain. These include **paracetamol** (also known as **acetaminophen**), **aspirin**, **diclofenac**, and **ibuprofen** (known in Kenya as **Brufen**).

Gabapentin: A medicine originally developed to treat epilepsy, now also used to treat neuropathic pain.

Amitriptyline: A medicine originally developed as an antidepressant, now also used to treat neuropathic pain.

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.

Summary and Key Recommendations

A community health worker examines a child in Kibera, the largest slum in Nairobi.

NEEDLESS PAIN

Photographs by Brent Foster

Kenya has high and increasing rates of childhood disease and child mortality. Hundreds of thousands of children suffer from AIDS, cancer, sickle cell disease, and other chronic, often fatal, or otherwise life-limiting illnesses, and they often experience severe, debilitating pain.

Almost all of this pain can be easily alleviated. Morphine, the mainstay medication for treating severe pain, is inexpensive and easy to administer—but widely unavailable in Kenya, especially for children. Palliative care—a field of medicine that seeks not to cure disease but to prevent suffering and improve quality of life—can be delivered at home, in a hospice, or a hospital. It focuses on treating pain and other physical symptoms, and providing psychosocial support,

A child looks through a bedroom window at Nyumbani, an orphanage for children living with HIV, near Nairobi, Kenya. Unlike many other facilities, the orphanage provides pain relief with morphine and palliative care to children suffering from severe pain and other distressing symptoms that can be associated with HIV.

A nurse reaches out for the hand of a baby at Nyumbani, an orphanage for children living with HIV, near Nairobi, Kenya.

complementing curative treatment. The two should be provided in parallel from the moment of diagnosis. Palliative care can even help curative treatment to succeed, for example, by enabling a child to eat, exercise, communicate, or adhere to a medication regimen.

While much of this report focuses on sick children's access to morphine and other pain medicines, because simple reforms could dramatically improve their availability and alleviate enormous suffering at low cost, palliative care for children means much more than morphine. It should include age-appropriate counseling for anxiety and other common psychological symptoms, play and distraction to ease pain and depression, and support for the entire family. It is essential that the Kenyan government not just improve pain treatment for children, but better integrate the full range of pediatric palliative care services into its health system.

In Kenya, pain medicines are not widely available to alleviate sick children's suffering. The World Health Organization (WHO) classifies oral morphine as an essential medicine and regards it as the drug of choice to treat moderate to severe chronic pain. Kenya's national medicines policy, too, calls oral morphine essential, meaning it should be a priority for public procurement and available in all national referral, provincial, and district hospitals. Yet the Kenya Medical Supplies Agency (KEMSA) does not procure oral morphine as it does other essential medicines, and this makes it more difficult for public hospitals to obtain it.

In fact, the Kenyan government has erected legal and regulatory barriers to using morphine to treat severe pain. The Kenyan narcotics law focuses on the illegal uses of morphine and other opioids and makes illicit possession punishable by life imprisonment and a heavy fine. There are exceptions for medical use, but no detailed guidelines about lawful possession by patients and health care workers, and some doctors and nurses perceive the current legislation to prohibit

Community health worker Mary Njoki speaks to a mother of twins during a home-based care visit March 6, 2010 in Mathare, a slum in Nairobi.

morphine. Kenya is also one of the few countries worldwide to levy an import tax on morphine powder.

Consequently, the medicine is unavailable at the vast majority of public hospitals in Kenya, in contravention of the country's international legal obligations. Only seven of approximately two hundred and fifty public hospitals have palliative care services and oral morphine for moderate to severe chronic pain. Medicines to treat neuropathic pain, caused by damaged nerves and common in AIDS and cancer patients, are also largely unavailable.

In Kenya, morphine is widely viewed not as an essential, low-cost tool to alleviate pain, but as dangerous. Health care professionals are rarely trained to treat pain and are often unaware that morphine can dramatically improve a sick child's well-being. Until recently, medical and nursing schools taught that morphine must only be administered to the terminally ill, because of unwarranted fear that it would cause addiction, and hospitals often only offer the drug when curative treatment has failed. Health workers do not routinely assess or effectively treat pain in children. Even at the seven public hospitals where morphine is available, doctors and nurses are sometimes reluctant to give it to a child, because they believe it amounts to giving up on the fight to save the child's life, and because unwarranted fears of addiction remain.

Health workers rarely communicate effectively with sick children and their families about the illness. They often fail to inform parents—and children who are old enough to understand—of the child's diagnosis, share basic facts regarding treatment, or make the prognosis clear. They rarely talk with children or their parents about their concerns and fears.

Although the majority of critically ill children in Kenya are cared for at home, the health system does little to support

(left) Toys that a mother kept in memory of her five-year-old son Gerard K. [not his real name], who died of HIV-related complications at the age of five in Kibera, Nairobi's largest slum. He suffered severe pain and had no access to adequate pain treatment or palliative care.

(above) After her son's death, his mother decided to become a community health worker.

(above) Anne Wanjiru, Co-ordinator of Groots Mathare Mother's Development Centre, and community health workers Mary Njoki and Florida Odongo, walk the streets of Mathare, a slum in Nairobi, on their way to a home-based care visit on March 6, 2010.

(right) The Kibera slum in Nairobi.

home-based palliative care. Parents are often unaware of the existence of strong pain medicines and therefore do not seek them for their children. The prevalence of HIV means that many sick children are orphans living with relatives or other caregivers, making them especially vulnerable. While most caregivers do their best to care for sick children, some mistreat and neglect them; the weak and overburdened child protection system often fails to reach these children.

The few focused palliative care services available in Kenya mostly serve adults. Around 15 private hospices provide important palliative care services, including some home-based care, but they serve mainly adults with terminal cancer. Some parents perceive hospices as places for adults dying of terminal disease, and are understandably reluctant to expose children to that environment. Without efforts to make hospices child-friendly environments—for example, by training staff to communicate well with children and providing toys and spaces for play—this situation is likely to remain unchanged.

Systemic problems in the health care system create conditions that stymie sick children in need of pain treatment. Many sick children lack access to health care adequate to get a basic diagnosis or curative treatment, much less palliative care. Local dispensaries and health centers are unable to diagnose or treat many conditions, and frequently refer children to district, provincial, and national hospitals. However they rarely provide transportation to families that cannot afford the travel costs. This means that health care often stops before it really begins. In addition, many children lack a name for what pains them or any hope of finding a way out of their distress.

Kenya has the highest per capita income in East Africa and is sometimes described as the economic powerhouse of the region. Yet its child health indicators are poor. Over the last

two decades, Kenya's under-five mortality rate rose from 105 to 128 deaths per 1,000 live births, while other, poorer, East African countries such as Uganda, Rwanda, and Ethiopia managed to reduce child mortality. Despite government efforts to subsidize child health, many children cannot access medical care because of prohibitive costs. In some cases, public hospitals have refused to discharge children when their families cannot pay hospital bills, and have detained them for months.

Under international law, the Kenyan government must progressively realize the right to the highest attainable standard of health. It is also obliged to fulfill certain minimum core obligations, including the non-discriminatory provision of access to health facilities, goods, and services; the provision of child health care; and the provision of drugs such as morphine that WHO classifies as essential medicines. The government must protect children from neglect, and from cruel, inhuman, or degrading treatment, which can include unreasonable denial of pain treatment. International law also emphasizes the essential role of international cooperation to fully realize the right to health.

Palliative care can be provided at a relatively low cost; for example, morphine is cheap to produce. WHO has recommended that governments develop national policies on palliative care, integrate palliative care into health services, ensure the availability of opioid pain medicines, and educate health professionals and the public about palliative care. For resource-poor countries, WHO has emphasized the importance of community-based palliative care, which can be provided at relatively low cost.

Some health professionals and health planners in Kenya fear that increased support for palliative care would diminish support for curative treatment. But palliative and curative treatment should go hand in hand. In recent years, the Kenyan

(left) Community health worker Mary Njoki examines a child during a home-based care visit March 6, 2010, in Mathare, a slum in Nairobi.

(above) A pharmacist takes morphine from a storage-room at Nairobi Hospice. Morphine powder (in white jars) mixed with water to make oral morphine solution (in brown bottles), is the cheapest way to provide pain relief for patients with severe chronic pain. In front of the oral morphine solution is injectable morphine, for treating acute pain.

The office of Groots Mathare Mother's Development Centre, in Mathare, a slum in Nairobi. Volunteer community health workers based at the centre provide home-based care in their community. March 6, 2010.

government and donors have focused on scaling up anti-retroviral treatment (ART) for HIV, and they have made impressive progress. But they have failed to address the continued suffering of tens of thousands of children who still lack access to anti-retroviral drugs; who lack food to eat to help tolerate the drugs; or who develop resistance to the drugs. And many children, including those on ART, experience serious pain and other distressing symptoms, and are in need of palliative care.

Access to pain treatment and palliative care is poor in many African countries. Some have no palliative care services at all. Uganda, a neighbor of Kenya, is a notable exception. It has made progress in improving the availability of palliative care. New policy and training has resulted in significantly improved access to palliative care services, including for children treated at home. In working towards improved palliative care services, the Kenyan government could learn from the Ugandan experience and adapt it to the Kenyan situation.

ETHIOPIA
UGANDA
SOMALIA
KENYA
Eldoret
Kakamega
Kisumu
Nanyuki
Nakuru
Embu
Nairobi
UNITED REPUBLIC
OF TANZANIA
Mombasa
SEVEN out of approximately TWO HUNDRED AND FIFTY public hospitals have oral morphine to treat severe chronic pain.
Location of a public hospital that has oral morphine to treat severe chronic pain
Location of a public hospital with no oral morphine to treat severe chronic pain

KEY RECOMMENDATIONS

TO THE GOVERNMENT OF KENYA

- **Urgently increase the availability of drugs for moderate to severe pain, in particular by making morphine tablets and morphine powder for oral solution available at all district, provincial, and national hospitals, in accordance with the Kenya National Drug Policy and Kenya Essential Drugs List. The Kenya Medical Supplies Agency (KEMSA) should centrally procure oral morphine.**
- **Create palliative care units with expertise in children's palliative care in district, provincial, and national hospitals, and raise awareness about the existence of these services.**
- **Roll out a program of support for home-based palliative care with expertise in children's palliative care through existing hospices and palliative care units or newly established services.**
- **Develop a policy and action plan on palliative care, with a specific focus on the needs of children.**
- **Ensure that the National Cancer Control and Prevention Bill and Strategy contain strong provisions addressing pain treatment and palliative care, including for children.**
- **Make pain treatment and palliative care an integral part of the HIV/AIDS response.**
- **Improve training for health workers on pain management and palliative care, including for children.**
- **Remove the tax on morphine powder.**

TO HEALTH DONORS

- **Ensure that all patients using donor-funded clinical services for life-limiting illness can access palliative care, either by providing it as part of the service, or by strengthening hospice and public palliative care services and facilitating access to them.**

Children play at Nyumbani, an orphanage for abandoned HIV+ children in Nairobi, Kenya. The orphanage, exceptional in Kenya, provides pain relief and palliative care to children suffering from severe pain and other distressing symptoms that can be associated with HIV.

Methodology

Field research for this report was carried out in February and March 2010 in Nairobi, including the Kibera and Mathare slums, and in Nyanza province, in the Bondo district and Kisumu. This research followed earlier field research and advocacy on children's access to HIV treatment in Kenya, based on over 150 interviews between August 2007 and August 2008, published in *A Question of Life of Death: Treatment Access for Children Living With HIV in Kenya*, December 2008.

In this report, the word "child" refers to anyone under the age of 18."[1] For this research, we interviewed the parents or guardians of 30 children, of whom 17 were girls and 13 were boys.[2] Nineteen of these children were present during the interviews. Four girls and two boys actively participated in interviews, in the presence of a parent. Eight of the children were in the care of a guardian who was not their parent, in most cases a relative. In addition, we interviewed two young women, aged 18 and 20, about events that occurred when they were children, in one case with a parent. Two interviews were with parents of children who had died.

Eleven of the children concerned had a confirmed diagnosis of cancer, and ten were confirmed to be HIV positive. Other children had burns, tuberculosis, malaria, and sickle cell anemia. In several cases the child's family members were not able to say precisely what their 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.

In addition, we carried out 50 interviews with health care workers, including 15 doctors, 18 nurses, 14 community health workers, a clinical officer, a nutritionist, and a hospice administrator. These interviews concerned barriers to pain treatment and palliative care generally, but the health care workers also related cases of another 31 children that they had cared for, including 14 who had died. Ten of these children had been diagnosed with cancer and seventeen were confirmed HIV positive. Some children had also suffered tuberculosis, malaria and pneumonia.

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[1] The Convention on the Rights of the Child states, "For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier." Convention on the Rights of the Child (CRC), adopted November 20, 1989, 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, India acceded to the CRC on December 11, 1992, art. 1.

[2] Under international law, anyone under the age of 18 is a child. Convention on the Rights of the Child (CRC), adopted November 20, 1989, 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, s.1.

In the Kenyan government, we interviewed representatives of the Ministry of Public Health and Sanitation, the Ministry of Medical Services, the Ministry for Gender and Children Affairs, the Pharmacy and Poisons Board, the Medical Practitioners and Dentists Board, the Kenyan Medical Research Institute, and district health authorities. We also interviewed several Kenyan and international experts on pediatric medicine, palliative care and opioid availability, as well as staff of Kenyan and international nongovernmental organizations working on health and child rights, several church-run orphanages and community health projects, the CDC, and WHO.

Carrying out interviews with children suffering from life-limiting illness, and their families, poses a number of methodological and ethical challenges.[3] In situations where children were too ill to be interviewed or were suffering pain, we deliberately refrained from conducting the interview. In some cases, we interviewed parents or guardians instead.

Children who have been traumatized by experiences of childhood illness, including untreated pain and other distressing symptoms, may be susceptible to re-traumatization and heightened stress when questioned by an unknown person.[4] For each child interviewed, we explained our work in age-appropriate terms. Before each interview we informed potential participants of the interview's purpose and the kinds of issues that would be covered, and asked whether they wanted to participate. We informed participants that they could discontinue the interview at any time or decline to answer any specific questions, without consequence. We took great care to interview children and their families in a friendly and sensitive manner, and ensured that the interview took place in a location where the interviewee's privacy was protected.

In order to protect the identities of the children interviewed, we have replaced all their names in this report with pseudonyms. Where information about the health status, including HIV status, of children or their family members was disclosed during interviews, this was kept strictly confidential.

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[3] National Children's Bureau, "Guidelines For Research," April 2003, http://www.ncb.org.uk/dotpdf/open percent20access percent20- percent20phase percent201 percent200nly/research_guidelines_200604.pdf (accessed March 29, 2010).

[4] The National Child Traumatic Stress Network, "Understanding Child Traumatic Stress," 2005, http://www.nctsn.org/nctsn_assets/pdfs/edu_materials/understanding_child_traumatic_stress_brochure_9-29-05.pdf (accessed March 29, 2010).

In order to avoid false expectations of support or financial assistance,[5] we made clear at the start of each interview that we were not able to provide direct individual support to those who spoke with us. Instead, when we encountered situations where people were in acute need of medical treatment, we tried to refer them to local NGOs or other actors who could assist them.

Interviews with health care workers and officials were conducted in English. Interviews with children and their families were carried out in English, Dholuo, Swahili, and Kikuyu. Where translation was necessary, it was generally provided by a health care worker known to the interviewee or by a translator with experience working with people with life-limiting illness.

[5] Erick O. Nyambedha, "Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya," *Social Science & Medicine,* vol. 10 (2008), pp. 1-9.

I. Background

The Importance of Palliative Care and Pain Treatment

Palliative care aims to improve the quality of life of people who face life-limiting illness, through pain and symptom relief, and through psychosocial support for patients and their families.[6] Its purpose is to provide care, not to cure.

While palliative care is often mistakenly seen as limited to end-of-life care, the World Health Organization (WHO) recommends that palliative care be available to all patients who have life-limiting illnesses, from the moment they are diagnosed. Life-limiting illnesses include a broad range of conditions that have painful or distressing symptoms; although there may be periods of healthy activity, there is usually at least a possibility of premature death.[7] When provided alongside curative treatment, palliative care not only improves the quality of life of patients and their families but can also improve the outcome of the treatment, for example, by improving patients' adherence to medication.[8]

Children's palliative care has been defined by WHO as "the active total care of the child's body, mind and spirit," as well as support for the family.[9] Children's palliative care includes efforts to assess and treat pain; the provision of medicines in appropriate formulations for children; support for the child through play, education, counseling and other methods; child-appropriate communication about the illness; and communication with, and support

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[6] World Health Organization (WHO), "Palliative care," undated, http://www.who.int/cancer/palliative/en/ (accessed February 12, 2010). For Human Rights Watch publications on the right to pain treatment, see *Unbearable Pain: India's Obligation to Ensure Palliative Care*, October 2009, http://www.hrw.org/sites/default/files/reports/health1009webwcover.pdf; *"Please, do not make us suffer any more…": Access to Pain Treatment as Human Right*, March 2009, http://www.hrw.org/sites/default/files/reports/health0309web_1.pdf.

[7] The International Children's Palliative Care Network (ICPCN) has identified four types of life-limiting condition: life-threatening illness for which curative treatment is possible but can fail (for example, cancer); illness where premature death is likely, but treatment can prolong life and allow long periods of health (i.e. HIV, cystic fibrosis, sickle cell disease); progressive illnesses with no treatment options, where treatment is exclusively palliative but may extend over many years (i.e. muscular dystrophy); and irreversible but non-progressive conditions that involve severe disability, health complications and risk of premature death (i.e. severe cerebal palsy, multiple disability following brain or spinal injury). ICPCN, "What is Children's Palliative Care," http://www.icpcn.org.uk/page.asp?section=000100010008000 4&itemTitle=What+is+Children percent92s+Palliative+Care percent3F (accessed April 23, 2010).

[8] Peter A. Selwyn and Marshall Forstein, "Overcoming the false dichotomy of curative vs. palliative care for late-stage HIV/AIDS," *Journal of the American Medical Association,* vol.290 (2003), pp. 806-814; Richard Harding et al., "Does Palliative Care Improve Outcomes for patients with HIV/AIDS: A systematic review of the evidence," *Sexually Transmitted Infections* , vol. 81 (2005), pp. 5-14; Justin Amery et al., "The Beginning of Children's Palliative Care in Africa: Evaluation of a Children's Palliative Care Service in Africa," *Journal of Palliative Medicine*, vol. 12 (2009), pp. 1015-1021.

[9] WHO, *National Cancer Control Programs: Policies and Managerial Guidelines*, (Geneva: World Health Organization 2002), p. 85, http://www.who.int/cancer/media/en/408.pdf (accessed February 12, 2010). See also Justin Amery, ed., *Children's Palliative Care in Africa* (New York: Oxford University Press, 2009).

for, the family.[10] It should also address child protection, as some severely ill children are vulnerable to exploitation, abuse, and neglect.[11] Hence, palliative care for children requires pediatric expertise, including on child-specific symptoms and diseases, as well as expertise in child psychology and child protection.

Palliative care is very important for children with life-limiting illness. For children, serious illness, pain, hospitalization, and invasive medical procedures are often profoundly disorienting and traumatizing and can cause great suffering. For parents and caregivers, watching a child suffer from symptoms and medical procedures, balancing the needs of the sick child with those of other children, and facing the prospect of the child's potential death, cause great distress. Pediatric palliative care can help both children and parents navigate these difficult circumstances by relieving distressing physical symptoms, minimizing pain caused by medical procedures, and enhancing communication among health care workers, children and parents about the child's illness and prognosis.

WHO recognizes palliative care as an integral part of health care that should be available to those who need it.[12] It has urged countries with limited resources to make palliative care services available because "the majority of patients presenting with advanced disease and urgently in need of symptom control must suffer without relief."[13]

When the majority of the population cannot access adequate health care, as in many parts of Africa, many health professionals and policy makers are more concerned with access to curative treatment than palliative care. Palliative care providers have even been accused of making people "comfortable with dying."[14] Yet palliative care is fundamentally a response to suffering. Where so many children suffer pain and are threatened with death, efforts to scale up curative treatment need to go hand in hand with efforts to improve access to palliative care.[15]

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[10] WHO, *National Cancer Control Programs*, p. 85. See also Amery, *Children's Palliative Care in Africa*.

[11] Amery et al., "The Beginning of Children's Palliative Care in Africa," *Journal of Palliative Medicine*.

[12] World Health Assembly, "Cancer prevention and control," WHA58.22, May 25, 2005, http://www.who.int/cancer/media/news/WHA58 percent2022-en.pdf (accessed on February 12, 2010).

[13] WHO, *National Cancer Control Programs*, p. 86.

[14] 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. On such views in Kenya, see subsection below on Lack of Skill in Assessing and Treating Pain.

[15] Ibid., pp. 505-512.

One key objective of palliative care is to offer treatment for pain.[16] Chronic pain is a common symptom of cancer and HIV/AIDS, as well as many other health conditions. Studies have shown that 60 to 90 percent of patients with advanced cancer experience moderate to severe pain, and that up to 80 percent of HIV patients suffer severe pain in the last phase of illness.[17] There is a widespread but incorrect perception that, since anti-retroviral therapy (ART) is now more widely available, palliative care should no longer be a priority in the HIV/AIDS response. But most patients worldwide who need ART still do not receive it, and patients who do receive ART often continue to experience pain, including severe pain caused by dysfunctional or damaged nerves (neuropathic pain). Simultaneous delivery of palliative care and ART can also improve treatment adherence.[18]

Moderate to severe pain has a profound impact on quality of life. It 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. People who live with chronic pain are also more likely to suffer from depression or anxiety.[19] The physical effect of chronic pain and the psychological strain it causes can influence the course of a disease; severe pain can actually lead to death.[20]

Most pain can be treated effectively with inexpensive and safe medicines. The standard tool for treating pain is WHO's Pain Ladder.[21] 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 strong opioids like morphine.

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[16] For an anthropological perspective on cancer pain in Africa, see Julie Livingston, "The Social Phenomenology of the Next Epidemic: Pain in Botswana's Cancer Ward," draft paper presented at an exploratory seminar on Anthropology and Social Innovation in Global Health, Princeton University, March 11-14, 2010 (on file at Human Rights Watch).

[17] For more detail, see Human Rights Watch, *"Please, do not make us suffer any more…"*, March 2009, pp. 5-10; Kathleen M. Foley et al., "Pain Control for People with Cancer and AIDS," in Dean T. Jamison et al., eds., *Disease Control Priorities in Developing Countries*, 2nd ed. (New York: Oxford University Press, 2006), p. 982.

[18] Selwyn and Forstein, "Overcoming the false dichotomy of curative vs. palliative care," pp. 806-814; K. Collins and R. Harding, "Improving HIV management in Sub-Saharan Africa: How much palliative care is needed?" *AIDS Care*, vol. 19, no. 10 (November 2007), pp.1304-1306; Family Health International, "Integrating palliative care into primary HIV care services: why it is important and how it can be done," August 11, 2009 (unpublished document on file at Human Rights Watch). At the end of 2008, only 42 percent of people in need of ART in low and middle income countries received it, including just 38 percent of children. AIDS caused 2 million deaths in the same year. UNAIDS, WHO, "Global Facts and Figures," 2009, http://data.unaids.org/pub/FactSheet/2009/20091124_FS_global_en.pdf (accessed June 18, 2010).

[19] 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.

[20] Amery, *Children's Palliative Care in Africa*, p. 98; WHO, *National Cancer Control Programs*, p. 83.

[21] WHO, "WHO's pain ladder," undated, http://www.who.int/cancer/palliative/painladder/en/ (accessed March 15, 2010). This has been developed for cancer but is also referred to for other conditions. See also WHO, *Cancer Pain Relief and Palliative Care for Children* (Geneva: World Health Organization, 1998), pp. 24-25.

While morphine can either be injected or taken orally, oral morphine is preferable for treatment of chronic pain, particularly for children, who often fear injections. Injectable and oral morphine are both included in the WHO Model List of Essential Medicines, which itemizes the drugs that should be available to all those who need them, and the WHO List of Essential Medicines for Children.[22] WHO is currently in the process of developing treatment guidelines on pain related to cancer, HIV, and other diseases for children.[23]

Due to their potential for abuse, morphine and other opioids are controlled medicines. This means that their distribution and dispensing is strictly regulated at international and national levels. Nevertheless, the 1961 Single Convention on Narcotic Drugs, the international treaty that governs drug control, 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."[24]

Palliative Care for Children in Africa

Sub-Saharan Africa has by far the world's highest rate of child mortality—half of all deaths of children under the age of five occur there. Close to one in seven children die before their fifth birthday, which amounted to 4.4 million deaths among the region's 135 million children younger than five in 2008. According to the United Nations, many countries in the region have made "little or no progress at all" towards Millennium Development Goal 4, which aims to reduce by two-thirds the mortality of children under the age of five.[25]

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[22] WHO, "WHO Model List of Essential Medicines," March 2009, http://www.who.int/selection_medicines/committees/expert/17/sixteenth_adult_list_en.pdf (accessed February 12, 2010), art. 2.2; WHO, "WHO Model List of Essential Medicines for Children," 2nd ed., March 2009, http://www.who.int/selection_medicines/committees/expert/17/second_children_list_en.pdf (accessed March 30, 2010), art. 2.2.

[23] WHO, "Scoping Document for WHO Treatment Guidelines on Chronic Pain in Children," 2008, http://www.who.int/medicines/areas/quality_safety/Scoping_WHOGuide_chronic_pain_children.pdf (accessed April 23, 2010). WHO is also developing similar guidelines for adults. WHO, "Scoping Document for WHO Treatment Guideline on Pain Related to Cancer, HIV and other progressive life-threatening illnesses in adults," October 14, 2008, http://www.who.int/medicines/areas/quality_safety/Scoping_WHOGuide_malignant_pain_adults.pdf (accessed March 18, 2010).

[24] Single Convention on Narcotic Drugs, 1961, adopted March 30, 1961, 520 U.N.T.S. 151, entered into force December 13, 1964, http://www.incb.org/incb/convention_1961.html (accessed January 15, 2009), preamble.

[25] United Nations Secretary General (UNSG), "The Millennium Development Goals Report 2009," July 6, 2009, http://www.un.org/millenniumgoals/pdf/MDG_Report_2009_ENG.pdf (accessed February 12, 2010), pp. 24-25. UNICEF, *The State of the World's Children: Special Edition* (New York: UNICEF, 2009), pp. 4 and 31. In 2001, UN member states adopted the Millennium Development Goals (MDGs), defining time-bound global objectives in the areas of health, education, and poverty eradication, to be reached by 2015. The MDG target for Africa is a reduction to about 61 per 1000 births by 2015. The Sub-Saharan Africa mortality rate for children under the age five was 184 per 1,000 live births in 1990, and 144 per 1,000 live births in 2008. United Nations International Children's Emergency Fund (UNICEF), "Child info," http://www.childinfo.org/mortality.html (accessed February 16, 2010).

HIV is one of the main causes of death in Sub-Saharan Africa. Although more children with HIV are now surviving due to the roll-out of ART, 230,000 children died of HIV in Sub-Saharan Africa in 2008.[26] In that year, WHO found that HIV was the leading cause of death among children below the age of five in six countries of Sub-Saharan Africa.[27]

Cancer is on the rise in Sub-Saharan Africa. Experts estimate that between 2000 and 2020, the number of people diagnosed with cancer annually in the region will increase by one million.[28] There are no conclusive studies explaining the increase in cancer in Sub-Saharan Africa, although it is commonly explained by changes in lifestyle and the high HIV prevalence, leading to some HIV-related cancers. Despite the rise in cancer, Africa has few and weak cancer care services. Reputable oncologists have estimated that as few as 5 percent of childhood cancers in Africa are cured, compared with nearly 80 percent in the developed world.[29]

Despite the urgent need, palliative care is rarely available in Africa. Many African countries have no public palliative care services and no access to morphine at all, including Senegal, Mali, Niger, Chad, Sudan, and Angola. Other countries offer palliative care services in a few specialist centers that are inaccessible for the majority of patients. South Africa, Zimbabwe, and Uganda have more developed palliative care services, but even these reach only a fraction of the people who need them.[30]

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[26] UNAIDS, WHO, "Mapping Progress Towards Universal Access," http://www.slideshare.net/UNAIDS/mapping-progress-towards-universal-access (accessed March 18, 2010).

[27] WHO, "Towards Universal Access, Scaling up priority HIV/AIDS interventions in the health sector," 2008, http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf (accessed March 18, 2010), p. 80 (table).

[28] Rebecca J. Lingwood et al., "The challenge of cancer control in Africa," *Nature Reviews Cancer*, vol. 8 (May 2008), p. 398-403. Cancer is also on the rise globally. According to experts, around 250,000 children develop cancer each year worldwide. Vittal Katikireddi, "100 000 children die needlessly from cancer every year," *British Medical Journal* , vol. 328, no. 7437 (February 21, 2004), http://www.ncbi.nlm.nih.gov/pmc/articles/PMC344290/ (accessed March 30, 2010), p. 422.

[29] International Union Against Cancer (UICC), "Cancer Control in Africa: Declaration presented during the Cancer Control in Africa meeting London, UK, 10-11 May 2007," http://www.uicc.org/index.php?option=com_content&task=view&id=15726&Itemid=631 (accessed February 12, 2010). "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.

[30] David Clark et al., "Hospice and Palliative Care Development in Africa: A Multi-Method Review of Services and Experiences," *Journal of Pain and Symptom Management*, vol. 33, issue 6 (June 2007); David Clark et al., "Mapping Levels of Palliative Care Development: A Global View," *Journal of Pain and Symptom Management*, vol. 35, issue 5 (February 2008); Justin Amery et al., "The beginnings of children's palliative care in Africa: evaluation of a children's palliative care service in Africa," Journal of Palliative Medicine; Richard Harding and Irene Higginson, Palliative Care in Sub-Saharan Africa: An Appraisal (London: King's College and Diana, Princess of Wales, Memorial Fund, 2004), http://www.cpsonline.info/content/resources/africa/pallcareinsubsaharanafrica.pdf (accessed February 16, 2010).

Children's palliative care is particularly weak in Africa, despite the enormous need. An evaluation of one of the few children's palliative care services—in Uganda—found that "one of the biggest barriers to good children's palliative care is failure to recognize that a child is in need of it."[31] Consequently, when a specialist children's palliative care service was established by a hospice in Uganda, the number of children referred and treated with chemotherapy and morphine rose sharply.[32]

The Kenyan Context

Kenya's challenges in providing pain treatment and palliative care to children represent those of many African countries: high child morbidity and mortality, and poor availability and accessibility of health services.

Child Mortality and Morbidity in Kenya

Although Kenya has the highest per capita income in East Africa and is sometimes described as the economic powerhouse of the region, its indicators for child health are poor.[33] Over the last two decades, Kenya's under-five mortality rate actually rose, from 105 to 128 children who will die before their 5th birthday for every 1,000 live births.[34] Other poorer East African countries such as Uganda, Rwanda, and Ethiopia have managed to reduce child mortality during the same period—in the case of Rwanda and Ethiopia, below the child mortality rate of Kenya.[35]

There are an estimated 140,000 to 170,000 children under the age of 15 living with HIV in Kenya.[36] Around 60,000 children need ART, but only about half of them are receiving this

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[31] Amery et al., "The Beginning of Children's Palliative Care in Africa," *Journal of Palliative Medicine*, p. 1019.

[32] Ibid. Chemotherapy can be a form of palliative care. Even if a child's cancer is considered incurable, chemotherapy may be used to shrink a tumor in order to reduce pain.

[33] "Africa, Countries," The World Bank resources page, undated, http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/0,,menuPK:258664~pagePK:146748~piPK:146812~theSitePK:258644,00.html (accessed March 30, 2010).

[34] "Info by Country: Kenya, Statistics," United Nations Children's Fund (UNICEF), http://www.unicef.org/infobycountry/kenya_statistics.html (accessed March 30, 2010). Figures are from 1990 and 2008.

[35] "Info by Country: Eastern and Southern Africa", United Nations Children's Fund (UNICEF), http://www.unicef.org/infobycountry/esaro.html (accessed March 30, 2010). Figures are from 1990 and 2008.

[36] "Kenya," The Joint United Nations Programme on HIV/AIDS (UNAIDS), undated, http://www.unaids.org/en/CountryResponses/Countries/kenya.asp (accessed March 30, 2010).

life-saving treatment. An estimated 15,000 babies are infected through mother-to-child transmission each year.[37]

As in other parts of Africa, cancer is believed to be on the rise in Kenya.[38] Although Kenya does not have a cancer registry, the government estimates that there are 80,000 cases of cancer (adults and children) per year.[39] According to WHO, an estimated 48,000 people die of cancer each year in Kenya.[40] Common cancers in children include cancer of the eye, Non-Hodgkin's lymphoma, leukemia and Burkitt's lymphoma, a cancer of the lymphatic system that often leads to tumor growth in the jaw area.[41]

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[37] Presentation by Dr. Irene Mukui, representative of the National STI/AIDS Control Program (NASCOP), Nairobi, November 30, 2009, direct attendance by Human Rights Watch researcher. Mother-to-child transmission of HIV includes transmission during pregnancy, birth or breastfeeding.

[38] Human Rights Watch interview with David Makumi, deputy president, Kenya Cancer Association, March 9, 2010.

[39] Human Rights Watch interview with Dr. Ochiba Lukandu, Division of Non-Communicable Diseases, Ministry of Public Health and Sanitation, February 26, 2010.

[40] Dagi Kimani, "New topic of cancer," *The East African*, June 1, 2009. These figures are only estimates, as the country lacks a cancer registry. The WHO estimate has been calculated using statistics from the World Health Organization Statistical Information System (WHOSIS) http://www.who.int/whosis/en/index.html (2009 data accessed as Excel spreadsheet, March 24, 2010). According to this data, Kenya's population is approximately 37,538,000 (2007), and its cancer mortality rate is 129.0 per 100,000 (2004).

[41] The only cancer registry is for Nairobi; it registered 213 cases of cancer among children between 2000 and 2002. Kenya Medical Research Institute/Nairobi Cancer Registry, "Cancer Incidence Report 2000-2002," October 2006, p. 30; International Agency for Research on Cancer (IARC)/World Health Organization (WHO), "Cancer in Africa, Epidemiology and Prevention," 2003, http://www.iarc.fr/en/publications/pdfs-online/epi/sp153/SP153.pdf (accessed March 18, 2010); J. Rainey et al., "Spatial clustering of endemic Burkitt's lymphoma in high-risk regions of Kenya," *International Journal of Cancer,* vol. 120 (2006), pp. 121-27.

II. Living with Pain: Children's Suffering Due to Lack of Palliative Care

The dearth of pediatric palliative care services in Kenya condemns many children to great suffering. In interviews with Human Rights Watch, children, their parents, and health workers told of experiences of untreated pain and lack of psychosocial support.

Patrick O., a 10-year-old boy from a rural area of Nyanza province, had sickle cell anemia, a blood disorder that includes episodes of severe pain and can be life-threatening. He told Human Rights Watch:

> The pain feels as if it comes from the bones. Sometimes it burns. Sometimes it aches.... When it was really bad, I could not go to school or even walk... At night, sleeping is not good because I have a backache. Sometimes one leg hurts and I cannot turn, so I need assistance ... sometimes I wake up in pain.... I feel bad when other children are learning [in school] and I am here.[42]

Patrick's mother said she sometimes buys paracetamol or ibuprofen for him, but Patrick said that these "provide no relief at all." He once received treatment at Moi Teaching and Referral Hospital, more than 100 miles away, but was unable to go back because of transportation costs.

Seven-year-old Elena C. was being treated for tuberculosis when Human Rights Watch visited her in the Mathare slum in Nairobi. Doctors told her parents to purchase over-the-counter pain medicines for her, but they said they could not afford them. Elena's father said that she suffers from joint pain, sores on her head, and a swollen jaw. He said that she sometimes cannot stand or walk, and "she cries all the time."[43]

Gerard K. from Kibera slum in Nairobi was five years old when he died. He was receiving ART, but died from suspected pneumonia and other complications associated with HIV/AIDS, while receiving only weak, over-the-counter painkillers.

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[42] Human Rights Watch interview with Patrick O., age 10, Nyangoma, Bondo district, Nyanza province, February 27, 2010.

[43] Human Rights Watch interview with father of Elena C., age seven, Mathare, Nairobi, February 26, 2010.

Gerard's mother said:

> He had severe pain sometimes, especially some abdominal pains… There were times that he would use those pain killers paracetamol and Brufen [ibuprofen] and the pain would … just persist … I could tell he was in a lot of pain because he was just stiffened and you could see he was really struggling because there were sounds he was making. So I could say that he died in pain.[44]

The mother of seven-year-old Nick M. from Kakamega in Western province described how her son suffered with a misdiagnosis and then inadequate pain medication before he eventually received chemotherapy and pain treatment at Kenyatta National Hospital:

> He has Burkitt's lymphoma of the belly. It started in 2008…. He received pain killers by the doctor [probably a clinical officer] at the health center. They did not help a lot. It was very painful; he used to cry a lot and could not sleep…. He suffered badly.[45]

We met several children living with chronic, painful diseases but who had never had a diagnosis or treatment. They spent their days sitting at home, enduring needless pain. One such child was four-year-old Jacob O. from Nyanza province. Jacob developed a large swelling or tumor on his back when he was one, and has suffered pain since then. He was visibly uncomfortable during our interview, leaning in a stiff posture on a chair but unable to sit. In the absence of any diagnosis or treatment plan, his mother was treating him with a simple pain reliever:

> It is still bad now, oozing and hurting…. He cannot sit, only lie or stand, because sitting is too painful. It sometimes affects his sleep. He sometimes cries through the night…. He gets Panadol [paracetamol] to ease the pain…[46]

Another such case was Rebecca A. from Nyanza province, who is now 20 years old. Rebecca has suffered from an undiagnosed condition causing pain on her left leg and upper side

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[44] Human Rights Watch interview with mother of Gerard K., Kibera, Nairobi, March 9, 2010.

[45] Human Rights Watch interview with mother of Nick M., age seven, Kenyatta National Hospital, Nairobi, February 25, 2010. The boy eventually reached Kenyatta National Hospital, where he had surgery and got pain treatment.

[46] Human Rights Watch interview with mother of Jacob O., age four, Nyangoma, Bondo district, Nyanza province, February 28, 2010.

since the age of two, according to her mother.[47] Her condition worsened when she was about 10. At the time of our visit, her left leg was thick and swollen, and she could not walk more than a few steps. Rebecca said:

> My leg is always very painful. At times I have a shooting pain through my leg and cannot stand up. Sometimes the pain is in the flesh, sometimes in the veins, sometimes right in the bone. Walking is very difficult. I can't walk to the next home [about 20 meters] or to the road [about 300 meters]. Going to the toilet it hard because sometimes my leg is too heavy to walk there. The leg is better if I sit, but even a short walk makes it worse. I can't allow anyone to touch my leg. Sometimes the pain comes all the way up my side. It has been painful my entire life. Sometimes the pain gives me difficulty breathing… Sometimes it is very painful at night. It is painful to turn so I have to lie still.[48]

Several palliative care doctors told us of children's suffering when health care workers fail to provide emotional support and communicate effectively. The head doctor at Nairobi hospice explained that children naturally reach out for answers and support:

> They ask you questions: "Why am I not going to school and my peers are going to school?" "Why am I not being allowed to play with my friends and my friends are playing out there?" "Why are you always taking me to the doctor and my friend so-and-so and neighbor are not always going to the doctor?"…. [Emotional support] is extremely important because they always ask, "Why is this happening to me?"[49]

A palliative care activist and doctor spoke of her experience of the lack of emotional support in a pediatric cancer ward:

> The nurses do not help the children cope with the fact that another child on the ward dies…. These children don't want candy, when you come they throw up their arms to be hugged, they want a cuddle.[50]

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[47] Human Rights Watch interview with mother of Rebecca A., Nyangoma, Bondo district, February 27, 2010.

[48] Human Rights Watch interview with Rebecca A., age 20, Nyangoma, Bondo district, February 27, 2010.

[49] Human Rights Watch interview with Dr. John Weru, head doctor at Nairobi Hospice, March 10, 2010.

[50] Human Rights Watch interview with Dr. Zipporah Ali, National Coordinator, KEHPCA, February 24, 2010.

Several doctors and nurses stated that health care workers lack training in effective communication and ways of providing emotional support to children with life-limiting illness. They also said that overworked doctors and nurses focus on medical procedures and lack the time to invest in providing emotional support to children.[51]

The Positive Effect of Palliative Care on Children's Lives

Several interviewees explained how palliative care can have a transformative impact on a child's quality of life. The doctor at Nairobi Hospice told Human Rights Watch about Fredrick B., a seven-year-old boy, who seemed to improve dramatically when he received morphine:

> He was not on pain medication for some time … When he came, we started him on pain killers. After he started on morphine, he requested his books to start writing. He had not asked for his books for two months, but at this time he requested for his books. He started demanding a PlayStation from the palliative care team so that he could play on the TV. Then he also requested his father. He requested his father to allow his friends to come, so that they can play.[52]

Christine L., now 18 years old, was diagnosed with breast cancer when she was 17. She told us how her mobility and capacities improved after she entered Kenyatta National Hospital and received morphine for her pain:

> Before I came [here], I couldn't eat or breathe well [because of the pain]. Now that I have been given medicine, I can eat and breathe. I couldn't sit down, but now I can. I had pain for more than a month. I told the doctor and nurses [at the Kijabe mission hospital] that I had pain. It took too long to get pain treatment in Kijabe. Here I got it immediately and started feeling well again.[53]

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[51] Human Rights Watch interview with a doctor treating children with cancer A, Nairobi, February 25, 2010; Human Rights Watch interview with head nurse and a second nurse, Bondo District Hospital, March 1, 2010; Human Rights Watch interview with Dr. Juliana Otieno, chief administrator and head of pediatrics, New Nyanza General Hospital, March 1, 2010.

[52] Human Rights Watch interview with Dr. John Weru, head doctor at Nairobi Hospice, February 25, 2010.

[53] Human Rights Watch interview with Christine L., age 18, Kenyatta National Hospital, Nairobi, February 24, 2010.

III. Barriers to Pain Treatment and Palliative Care for Children in Kenya

In Kenya, a sick child encounters almost insurmountable obstacles to receiving pain treatment and other palliative care.

There is no overarching government policy on palliative care, and few palliative care services. Existing services are poorly integrated into the public health system and rarely geared towards the needs of children. Oral morphine, the medicine of choice for the treatment of severe chronic pain, is largely unavailable in Kenya's public hospitals. Even when the drugs are available, health workers refrain from using them because they lack guidance on the medicinal use of opioids and perceive morphine as dangerous. At Kenya's medical and nursing schools, doctors and nurses receive little training on palliative care and pain treatment. As a result, health workers lack skills in assessing and treating pain, and communicating appropriately with children and their families about the child's illness.

Children's caregivers often do not know about existing palliative care services and may consider pain to be inevitable. As a result, they may neglect to take children for medical care. The Kenyan government has done little to inform the public about pain treatment and palliative care, or to protect vulnerable children in need of medical care. Furthermore, the government has failed generally to make health care for children more affordable and accessible, making palliative care only one part of a health system that shuts out large numbers of sick children.

Under international law, Kenya has an obligation to progressively realize the right to the highest attainable standard of health.[54] This includes several core obligations relevant to palliative care for children. States must provide essential drugs as defined by WHO, ensure access to child health care, and provide training for health personnel.[55]

WHO has explicitly stated that all countries, even poor ones, should allocate resources to palliative care:

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[54] For details see legal section below.

[55] 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), paras. 43-44, The General Comment is based on the 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; see also CRC, art 24.

> The fundamental responsibility of the health profession to ease the suffering of patients cannot be fulfilled unless palliative care has priority status within public health and disease control programmes; it is not an optional extra. 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.[56]

WHO has urged countries to adopt national policies that support pain treatment and palliative care; enact educational programs for health care personnel and the public; and ensure the availability of palliative care medicines, including morphine. It has noted that these measures "cost very little but can have a significant effect."[57] For countries with limited resources, like Kenya, WHO has recommended implementing palliative care services in the community, in people's homes, and in medical institutions that deal with large numbers of patients in need.[58]

Palliative Care and Pain Treatment on the Margins

Lack of Palliative Care Services and Poor Integration into the Health System

Kenyan public health facilities have very few palliative care services where health professionals are trained to offer pain and symptom relief along with psychosocial support. Instead, privately funded hospices provide palliative care, functioning relatively separately from other parts of the health care system. The majority of hospice patients are adults with terminal cancer; however, this is only a small fraction of cancer patients in need of hospice care. Adults suffering from pain as a result of HIV and other diseases are rarely referred to palliative care services, and children even less often.[59]

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[56] WHO, *National Cancer Control Programs*, p. 86.

[57] WHO, *Cancer Pain Relief: with a guide to opioid availability,* 2nd ed. (Geneva: World Health Organization, 1996), http://whqlibdoc.who.int/publications/9241544821.pdf (accessed April 22, 2010).

[58] Ibid. Some similar recommendations were made in other documents, such as; World Health Organization (WHO), *National Cancer Control Programs,* p.86-88; *Cancer pain relief and palliative care in children*, pp. 71-72.

[59] A survey of seven Kenyan hospices found that they served 5,426 cancer patients between July and December 2008, and 1,586 patients with HIV during the same period. KEHPCA has been carrying out workshop with hospices to sensitize them to the palliative care needs of patients living with HIV. KEHPCA, "Annual Report," 2008, pp. 8 and ii. Regarding the referral of children, see next section below.

In an important step towards integrated palliative care, a few public hospitals have established palliative care units in recent years.[60] These include the palliative care unit at the country's largest national referral hospital, Kenyatta National Hospital (Nairobi), and palliative care units at three provincial hospitals, Embu Provincial General Hospital, Machakos Level 5 Hospital (both serving Eastern province), and Nakuru Provincial General Hospital (Rift Valley province). In addition, two district hospitals offer palliative care for the districts they serve, Port Reitz District Hospital (Coast province) and Nanyuki District Hospital (Rift Valley province). A provincial hospital in Kakamega contains a hospice that is similar to a palliative care unit. [61] There are no palliative care services at all in the north of the country. Overall, palliative care services remain few and far between.

Staff in palliative care units assess patients' needs and provide pain treatment and other symptom relief. Few counseling services are available, but doctors and nurses trained in palliative care described efforts to address children's psychosocial needs, especially reuniting children with family members. Staff in palliative care units also have the important role of educating fellow health workers about the importance of palliative care. Palliative care units do not have patients in their full-time care—they serve outpatients and also visit patients in the wards—so they must work with other hospital staff to address each patient's needs. This is not always easy, as palliative care units receive referrals from a patient's main doctors, and are expected to be deferential to them. Staff of one palliative care unit found that doctors and nurses are as reluctant to refer patients to the palliative care unit as to a hospice because they consider such a referral a defeat in the face of a patient's disease.[62]

The creation of palliative care services, and their integration into existing health services, is a key WHO recommendation to governments. Political and institutional commitments to palliative care are critical to ensuring functional delivery of services. Other recommended measures—such as training—can only come to fruition if doctors and nurses work in health

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[60] Kenya's public health system is classified into six levels. The community is at level one, dispensaries are at level two, health centers are at level three, and hospitals are at levels four, five, and six. There are national (tertiary), provincial (secondary), and district and sub-district (primary) hospitals. Ministry of Medical Services, Government of Kenya, *Strategic Plan 2008-2012*, p. 14, http://www.medical.go.ke/dmdocuments/MOMS percent20Strategic percent20Plan percent20-percent202008 percent20- percent202012.pdf (accessed April 22, 2010). A health center is generally staffed by a clinical officer and a nurse and a dispensary generally has only nurses. Human Rights Watch interview with Medical Officer for Public Health, Bondo District, March 1, 2010.

[61] KEHPCA, "Annual Report" 2008, p. 11; Human Rights Watch interview with Dr. Zipporah Ali, National Coordinator, KEHPCA, March 3, 2010. In addition, some nongovernment mission hospitals have also established palliative care units. A few public hospitals, New Nyanza Provincial General Hospital and Moi Referral Hospital, offer some palliative care services but do not have a separate palliative care unit. Regarding the availability of morphine in hospitals, see section below on Poor Drug Availability.

[62] Human Rights Watch interview with Dr. Esther Munyoro, head of the palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010; Human Rights Watch interview with nurse A, palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010.

facilities where they are able to practice the skills they have learned.[63] Hospital leaders can create such an environment by developing and regularly evaluating policies on pain management and palliative care, with particular attention to children. Such policies should address practical issues such as assessing pain as part of routine patient assessment, pain treatment protocols, as well as staff training. In particular, hospitals should regularly assess whether children are receiving appropriate pain and symptom management and psychosocial support.[64]

Some private hospitals in Kenya include pain on the initial assessment form that nurses fill in when they first encounter a new patient.[65] Small reforms like this can be an important part of institutionalizing pain management.

Lack of Services for Children's Pain Treatment and Palliative Care

There is no specialist palliative care service for children in Kenya's public health system. Even the private children's hospital in Nairobi does not have such a service.[66] Two public hospitals provide limited palliative care for children with cancer on their pediatric oncology wards.[67]

Where palliative care services exist in hospitals and privately-run hospices, they are geared towards adults and rarely treat children. A 2007 survey found that a hospice in Eldoret (Rift Valley province) treated no children at all.[68] St. Catherine's Hospice in Nyanza province was established to care for children with cancer, but in several years of operation, only a handful of children have been referred there, so most of its patients are adults.[69]

The fact that most palliative care facilities serve mostly adults probably contributes to low numbers of referrals of children. One parent described the local hospice as "not child-friendly," even though the hospice provides palliative care through outpatient visits and

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[63] Jack Jagwe and Anne Merriman, "Uganda: Delivering Analgesia in Rural Africa: Opioid Availability and Nurse Prescribing," *Journal of Pain and Symptom Management*, vol. 33, no. 5 (May 2007), p. 550.

[64] Human Rights Watch email correspondence with Neil L. Schechter, director, Pain Relief Program, Connecticut Children's Medical Center, March 23, 2010.

[65] Human Rights Watch interview with Dr. Hellen Karyuki, Kenyan Association for the Study of Pain, February 25, 2010; Human Rights Watch interview with David Makumi, March 9, 2010.

[66] Human Rights Watch interview with head nurse, Gertrude's Children's Hospital, Nairobi, March 5, 2010.

[67] New Nyanza General Hospital in Kisumu and Kenyatta National Hospital in Nairobi.

[68] Between 8 and 10 percent of patients at Nairobi, Meru, and Coast Hospices were children. The exception was Kisumu Hospice, where 60 percent of patients were children. KEHPCA, "Annual report 2008," Annex P.ii.

[69] Human Rights Watch interview with hospice administrator, St. Catherine's Hospice, March 4, 2010.

home-based care.[70] Doctors are also often reluctant to refer children to palliative care services, as they believe that referring a child to a hospice amounts to "giving up on" the child.[71]

Under international law, governments are obligated to take measures to ensure the availability of child health care. WHO has specifically recommended national cancer pain relief programs for children.[72]

Lack of Community-Based Pain Treatment and Palliative Care

Home-based care

When parents look after a very sick child, they often—although not always—prefer to have the child at home.[73] But the health care system does not provide support for adequate pain treatment and palliative care in the home, in contrast to home-based care for people living with HIV, which is relatively well developed.

In the last two decades, home-based care provided by community health workers, who are lay volunteers, has become the most common form of care for people living with HIV in Kenya.[74] The community health workers are attached to NGOs, churches, or government health centers working on HIV. If they are connected to a public health facility, they are trained and supervised by a community health extension worker who is a paid staff member.[75] Community health workers raise awareness about HIV prevention and other health issues. They regularly visit HIV-positive patients, monitor their adherence to treatment, give referrals to health facilities, and provide basic health advice and physical care, such as help with washing and dressing wounds. Community health workers play a vital role in linking a sick child and the health system. For example, they frequently convince

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[70] Human Right Watch interview with James Nyaga, founder, Hope for Cancer Kids, February 24, 2010.

[71] Human Rights Watch interview with Dr. Esther Munyoro, Kenyatta National Hospital, February 24, 2010; Human Rights Watch interview with Dr. John Weru, March 25, 2010; Human Rights Watch interview with Dr. Juliana Otieno, March 1, 2010.

[72] WHO, *Cancer pain relief and palliative care in children*, p. 71.

[73] Human Rights Watch interview with James Nyaga, founder, Hope for Cancer Kids, February 24, 2010; Human Rights Watch interview with hospice administrator, St. Catherine's Hospice, March 4, 2010; Human Rights Watch interview with Dr. John Weru, March 25, 2010.

[74] WHO, "Community Home-Based Care: Action Research in Kenya," WHO/NMH/CCL/01.01, 2001; Charles Olango, "An ethnographic study of home-based care for people living with HIV/AIDS in Nyang'oma Division, Bondo District, Western Kenya," MA Thesis, Institute of Anthropology, Gender and African Studies, University of Nairobi, 2008 (unpublished, on file at Human Rights Watch).

[75] Ministry of Health, "Taking the Kenya Essential Package for Health to the Community. A Strategy for the Delivery of Level One Services," June 2006.

parents or guardians to take the child to a health facility for HIV testing, treatment, or other medical care.[76]

Community health workers have uneven levels of training and access to resources to provide home-based care. Some have basic care kits, often provided by health donors, consisting of such items as bandages, antiseptic, and basic pain medicines. Unfortunately, others have no supplies at all. In rural areas, community health workers are not able to reach many patients because they lack transportation, and could help many more people if they were equipped with bicycles. Community health workers are also more effective if they have strong links with doctors and nurses. For example, if they can bring a nurse to visit a patient in need of more expert attention, or refer a patient to a doctor who they know will waive fees for a destitute patient.

A minority of community health workers has training in palliative care, but this tends to focus on HIV, and the basic symptom relief and counseling that non-professionals can provide.

There is less home-based care for patients suffering from diseases other than HIV. For example, parents looking after children with cancer at home rarely get any support.[77] A few private hospices, such as the Nairobi and Kisumu hospices, provide home-based palliative care, but these can reach only a small fraction of patients in need, and are not focused on children.[78]

Ann Wanjiru, the head of a community-based group providing home-based care in a Nairobi slum, explained how the absence of palliative care services made it very difficult to care for child patients at home:

> It is very frustrating because once you find that a child is crying, [and] you have already given him some medicine like aspirin and still a child cries, you

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[76] Human Rights Watch, *A Question of Life or Death*, pp. 78-80; Human Rights Watch interview with community health worker, Nyangoma, February 28, 2010; Human Rights Watch interviews with community health workers, Mathare, Nairobi, February 26, 2010.

[77] Human Rights Watch interview with James Nyaga, founder of Hope for Cancer Kids, Nairobi, February 24, 2010.

[78] Human Rights Watch interview with John Weru, March 25, 2010; Human Rights Watch interview with palliative care nurses, Kisumu Hospice, March 2, 2010.

> feel so bad. So you try to put some wet clothes on the body of the child so their temperature can go down, but it is really very painful for us.[79]

Given the large number of children with serious illness in Kenya and the general preference of many parents for care at home, it is essential to improve and support home-based care, and shift some palliative care tasks to community health workers.

WHO has urged countries with limited resources, such as Kenya, to develop community-based palliative care services:

> In low-resource settings it is important to ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care in targeted areas, and that there is high coverage of patients through services provided mainly by home-based care. Home-based care is generally the best way of achieving good quality care and coverage in countries with strong family support and poor health infrastructure.[80]

As the example of HIV has shown, community health workers can play a positive role in ensuring that children access treatment. This could be extended to pain treatment and palliative care, so that community workers could help child patients get a diagnosis and seek the right treatment, as well as provide practical support and treat symptoms, offer psychosocial support, and create links with community support groups, such as HIV support groups.

Community health workers are usually unpaid, yet many work dozens of hours each week as a compassionate response to the enormous need for basic health care in their communities. In some programs, retention is poor. Modest compensation would improve retention, ensuring that patients benefit from investments in community health worker training programs.

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[79] Human Rights Watch interview with Ann Wanjiru, head of GROOTS Mathare Mothers Development Centre, Mathare, February 26, 2010.

[80] WHO, *National Cancer Control Programs,* p. 91

Orphanage-Based Care

There are numerous orphanages in Kenya, many of which care for children living with HIV.[81] Children in these orphanages sometimes suffer from severe HIV-related or treatment-related pain. Some die when they become resistant to ART. Others die because they are put on treatment too late or have not adhered to treatment.

There is hardly any support from the public health system for care in orphanages. While some larger orphanages have trained health workers on staff, or enjoy regular visits from doctors, many others do not. [82]

At one orphanage, a staff member remembered the case of Henry K., who became resistant to all anti-retroviral combinations available in Kenya and died at the age of 10. He received morphine only during the last few days of his life, after suffering severe pain:

> He often had abdominal pain, headaches, constant vomiting, and sometimes diarrhea. He was prone to respiratory infections and so was periodically on antibiotics…. He also had depression because he knew he was going to die. We tried to control his pain with Brufen [ibuprofen] and paracetamol…. In his last week, he had high blood pressure, was on an IV [intravenous] drip, couldn't eat, and had generalized pain…. One night, the cardiologist stayed with him for three hours. The next day, Dr. [name withheld] prescribed morphine for him.[83]

Staff at the same orphanage also looked after an 18-year-old girl who developed resistance to ART and died. Among other things, she suffered from rashes, headaches, stomach pain, and bleeding from her mouth and nose. She was given only basic pain medicines until very shortly before her death, when a doctor prescribed morphine for her.[84]

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[81] On some of the challenges of care in Kenya's orphanages, see Carlos Alviar and Roger Pearson, "Cash transfers for vulnerable children in Kenya: from political choice to scale-up," UNICEF, October 2009, http://www.unicef.org/socialpolicy/files/Postscript_Formatted_PPCI_cash_transfers_in_Kenya_Final_Dec_15.pdf (accessed April 22, 2010), p. 12.

[82] Nyumbani orphanage in Nairobi has a staff nurse with knowledge of palliative care, and health care workers administer morphine to children who suffer from severe pain. In one case, a doctor who regularly visits the orphanage prescribed an extended course of morphine to a 13-year-old boy who had become resistant to ART and eventually died. Human Rights Watch interview with staff members of Nyumbani orphanage, March 9, 2010.

[83] Human Rights Watch interview with staff member of orphanage, Nairobi, March 4, 2010.

[84] Human Rights Watch interview with head of orphanage, Nairobi, March 3, 2010.

Absence of a Government Policy on Palliative Care

Although WHO has called on countries to establish a national policy and program for pain relief and palliative care, Kenya has no such policy or strategy.[85] The national health plans of the Ministry of Medical Services and the Ministry of Public Health and Sanitation for 2008 to 2012 include specific targets for other key issues, such as HIV, tuberculosis, and malaria prevention and treatment, access to clean water and sanitation, and maternal and reproductive health, but do not mention palliative care or pain treatment.[86]

Kenya's newly adopted National HIV/Aids Strategic Plan 2009/10-2012/13 makes just one brief reference to palliative care and no mention of pain, even though the Kenya Hospices and Palliative Care Association (KEHPCA) provided extensive input on the topic.[87] It is particularly disappointing that the government and donors have failed to address the issue of pain treatment and palliative care in the context of the HIV response, for which many policies and guidelines have been developed.

More positively, the government is currently preparing a Cancer Prevention and Control Bill, and a cancer control strategy, with the overall goal to "improve treatment, pain relief and palliative care of people affected by cancer."[88] The current draft bill, which establishes a National Cancer Prevention and Control Institute, also includes palliative care as integral part of cancer care.[89]

Given the general absence of policy guidance on palliative care from the government, it is not surprising that Kenya lacks a policy or strategy on pediatric palliative care, even in policy documents on child health care. One government survey on child health care does not include pain assessment in its description of a complete physical examination of a sick child.[90]

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[85] WHO, *National Cancer Control Programs,* p. 88.

[86] Ministry of Medical Services, Government of Kenya, *Strategic Plan;* Ministry of Public Health and Sanitation, "Strategic Plan 2008-2012," December 2008, http://www.publichealth.go.ke/index.php?option=com_docman&task=cat_view&gid=15&Itemid=94 (accessed March 27, 2010).

[87] National AIDS Control Council, *Kenya National AIDS Strategic Plan: Delivering on Universal Access to Services,* (Nairobi: Office of the President, November 2009), http://www.nacc.or.ke/2007/images/downloads/knasp_iii_document.pdf (accessed April 22, 2010), p. 34. For specific policies on opioid medicines, see the section below on drug availability.

[88] Ministry of Public Health and Sanitation, Ministry of Medical Services, *National Strategy for the Prevention and Control of Cancer,* draft, November 2009 (on file at Human Rights Watch); Human Rights Watch interview with Dr. Lukandu, Division of Non-Communicable Diseases, Ministry of Public Health and Sanitation, February 26, 2010.

[89] The Cancer Prevention and Control Bill, 2009 (draft on file at Human Rights Watch).

[90] Annah Wamae et al., Kenya working papers No.2: "Child Health Services in Kenya," (Nairobi: Ministry of Public Health and Sanitation/USAID/UNICEF) January 2009,http://www.usaid.gov/ke/ke.buproc/Child_health_services.pdf (accessed April 22,

Lack of Availability of Pain Drugs

The poor availability of pain treatment in Kenya's health facilities is reflected in the country's overall consumption of opioid medicines, which governments report annually to the International Narcotics Control Board (INCB), a body charged with monitoring the implementation of UN drug conventions.[91] Between 2004 and 2008, the last year for which figures were published, Kenya used an average of 8.6 kg of morphine annually.[92] This is sufficient to adequately treat moderate to severe pain in approximately 1,500 adult patients with terminal cancer or HIV/AIDS, less than 2 percent of those estimated to require such treatment in Kenya.[93] According to the INCB, in 2008, Uganda, Kenya's far poorer neighbor, used twice as much morphine per person as Kenya; South Africa, 18 times more; and Canada, 240 times more.[94]

Our research has identified a number of key barriers to the availability of essential palliative care medicines, including a failure to implement the current medicines policy; fears among health care providers about prescribing opioid medicines; the lack of central procurement of morphine; and the drug's inflated cost.

The UN Committee on Economic, Social and Cultural Rights has defined governments' core obligations under the right to health in the International Covenant on Economic, Social and Cultural Rights to include the provision of essential medicines, as defined by WHO.[95] These include oral and injectable morphine and codeine for pain treatment in adults and children.[96] WHO stresses that governments must explore ways for essential drugs to be made available at the lowest possible cost, and create laws and policies to support opioid

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2010), p. 23; Ministry of Public Health and Sanitation/ Ministry of Medical Services, "Child Survival and Development Strategy 2008-2015," January 2009, http://www.usaid.gov/ke/ke.buproc/index.html (accessed April 22, 2010).

[91] States are required to report their "consumption" of morphine and other opioid medicines to the INCB as part of the system of international drug control established by the Single Convention on Narcotic Drugs. A drug is considered "consumed" when it has been "supplied to any person or enterprise for retail distribution, medical use or scientific research." Single Convention on Narcotic Drugs, art. 1(2).

[92] INCB, *Narcotic Drugs: Estimated World Requirements for 2010 – Statistics for 2008*, T.10.XI.2 (New York: United Nations, 2010) http://www.incb.org/incb/en/narcotic_drugs_2009.html (accessed March 30, 2010), p. 219.

[93] This calculation is based on an estimate by Foley and others that 80 percent of terminal cancer patients and 50 percent of terminal AIDS patients will require an average of 90 days of pain treatment with 60 to 75 mg of morphine per day. Kathleen M. Foley et al., "Pain Control for People with Cancer and AIDS" in *Disease Control Priorities in Developing Countries*, pp. 981-994.

[94] INCB, *Narcotic Drugs: Estimated World Requirements for 2010 – Statistics for 2008*, pp. 260, 262 and 267.

[95] 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, U.N. Doc. E/C.12/2000/4 (2000), para 83.

[96] WHO, "WHO Model List of Essential Medicines"; WHO, "WHO Model List of Essential Medicines for Children," art. 2.2.

drug availability for pain relief and palliative care.[97] Kenya has failed to meet these international legal obligations regarding essential pain medicines.

Poor Availability of Morphine and Other Opioids

Kenya has approximately two hundred and fifty public hospitals, but only seven of them offer treatment with oral morphine for severe chronic pain. These are Kenyatta National Hospital (Nairobi), Moi Teaching and Referral Hospital, Nakuru Provincial General Hospital (both Rift Valley province), Embu Provincial General Hospital (Eastern province), New Nyanza Provincial General Hospital (Nyanza province), Kakamega Provincial General Hospital (Western province), and Nanyuki District Hospital (serving one district in Rift Valley province).[98] Some of these hospitals have oral morphine because they are near a hospice that supplies it to them.

Injectable morphine is slightly more widely available. All provincial hospitals have injectable morphine for acute pain treatment—for example, for accident trauma or after operations—and some district hospitals stock it for the same purpose.[99] But injectable morphine is far less suitable for the treatment of chronic pain because it requires several injections a day, which is difficult for children and patients who are emaciated by cancer or HIV/AIDS.

National and provincial hospitals also generally stock dihydrocodeine, a weak opioid, but it is generally not available in district hospitals.[100]

In our interviews, parents repeatedly told us that they had visited district hospitals with their children but had not received adequate treatment for the children's pain. Such insufficient treatment of severe pain in children occurred at district hospitals in Kisii, Rachuonyo, Bondo, Homa Bay (Nyanza province), Busia (Western province), Naivasha (Rift Valley province),

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[97] WHO, *National Cancer Control Programs,* p. 87; WHO, *Cancer Pain Relief,* p. 43.

[98] KEHPCA, "Annual Report," 2008; Human Rights Watch interview with Dr. Zipporah Ali, National Coordinator, KEHPCA, February 24, 2010. New Nyanza Provincial General Hospital does not stock morphine, but uses oral morphine from a hospice nearby. Several other nongovernmental health facilities also have morphine, including health facilities in Nairobi's slums. However, even the leading private children's hospital lacks oral morphine: Human Rights Watch interview with head nurse, Gertrude's Children's Hospital, Nairobi, March 5, 2010. Port Reitz district hospital, which has a palliative care unit, also lacks oral morphine.

[99] Human Rights Watch interview with Dr. Mikal Ayiro, Pharmacy and Poisons Board, March 3, 2010; Human Rights Watch interview with pharmacist, Nairobi Hospice, March 10, 2010. Most hospitals also stock pethidine to treat acute pain; it is also unsuitable to treat chronic pain. For details, see text box below.

[100] Human Rights Watch interview with Medical Officer for Public Health, Bondo District Hospital, March 1, 2010; Human Rights Watch interview with medical officer in charge, District Medical Office, Kisumu East, March 2, 2010; Human Rights Watch Interview with Dr. Mikal Ayiro, March 3, 2010; Human Rights Watch interview with head nurse and a second nurse, Bondo District Hospital, March 1, 2010.

Karatina (Central province), and Nairobi (Mbagathi district hospital).[101] For example, the sister of 16-year-old Judith A., who has cancer and is from Kisii in Nyanza province, told us:

> The problems started in June 2009…. She used to be in pain. She used to cry. She had a lot of pain in the mouth, so she could not eat. When the pain got worse, some growth started appearing. She was in form 3 [third year of secondary school]. After the summer she did not go back to school. When the growth started, we went to see a doctor at the district hospital in Kisii. He said he cannot handle the case and referred her to Kenyatta National Hospital. [In Kisii district hospital], she was given pain medication, paracetamol. It did not help very much, she was still in pain.[102]

A palliative care nurse at Kenyatta National Hospital told us about Kevin N., a 12-year-old boy with cancer (rhabdomyosarcoma) who had come to the Karatina district hospital with "unbearable pain" in late 2009. The hospital did not have medications strong enough to treat his pain. To get treatment, he traveled 160 kilometers to Nairobi. Within 24 hours of arriving at Kenyatta National Hospital, doctors put him on morphine, which eased his pain.[103]

A nurse in the Bondo District Hospital expressed her frustration at the lack of strong pain medications available to her, saying:

> We have no pethidine [an opioid], no DF-118 [dihydrocodeine] and no morphine…. We have children here with advanced HIV, some are in severe pain. The pain management for children with advanced HIV is not enough.[104]

A community health worker in the Mathare slum of Nairobi complained that strong pain drugs are not available in many hospitals:

> We wish … that hospitals are equipped with such medicines [morphine] so that whenever you find a child who is in great pain when you go to the hospital … you don't have to give your usual aspirin or paracetamol.[105]

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[101] Human Rights Watch interviews with relatives of child patients at New Nyanza General Hospital and Kenyatta National Hospital, Nairobi, February and March 2010.

[102] Human Rights Watch interview with sister of Judith A., age 16, Kenyatta National Hospital, Nairobi, February 24, 2010.

[103] Human Rights Watch interview with nurse B, palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010.

[104] Human Rights Watch interview with head nurse, Bondo District Hospital, March 1, 2010.

[105] Human Rights Watch interview with Ann Wanjiru, head of GROOTS Mathare Mothers Development Centre, Mathare, February 26, 2010.

Even basic, non-opioid pain medicines are not as widely available as they should be. During our visit to the Bondo District Hospital, nurses complained that they had no diclofenac, a basic non-opioid pain reliever. One nurse showed us a child who had suffered severe burns the previous day and said: "If we had diclofenac we would give it, but we don't have it here."[106]

The poor availability of morphine and dihydrocodeine at district and provincial hospitals contradicts the goals of Kenya's Essential Drugs List. In the case of morphine, which is classified as an essential medicine by WHO, it is also a violation of a core obligation under the right to the highest attainable standard of health.

Failure to Implement Kenya's Medicines Policy

The Kenya National Drug Policy provides the framework for the procurement, distribution, and use of medicines in Kenya.[107] The policy aims to ensure the rational use and constant availability of drugs at affordable prices.[108] At the heart of the Kenya National Drug Policy is the Kenya Essential Drugs List. It is the basis for public sector procurement, prescribing, and dispensing; medical education; and training programs for health professionals.[109]

Kenya's Essential Drugs List includes the opioids morphine, dihydrocodeine, and pethidine, classifies them as essential for district, provincial, and national hospitals, and stipulates that morphine must be available as an oral solution, a tablet, and in its injectable form.[110] The list also includes several basic pain medicines, such as aspirin and paracetamol, which must be available to community health workers.[111]

Kenya is currently in the process of revising its Essential Drugs List, which differs from the WHO Model List of Essential Medicines and the WHO List of Essential Medicines for Children, which do not include dihydrocodeine and pethidine (see text box).[112]

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[106] Human Rights Watch interview with head nurse, Bondo District Hospital, March 1, 2010.

[107] Republic of Kenya, Ministry of Health, "The Kenya National Drug Policy," July, 1994, http://collections.infocollections.org/whocountry/en/d/Jh4332e/ (accessed March 30, 2010).

[108] Ibid., art. 1.2.

[109] Ibid., arts. 2.1, 2.4, 2.5, 3.2, 3.4, and 6.4.

[110] Ibid., art. 2.2. Injectable pethidine and dihydrocodeine tablets are also listed as essential drugs for referral, provincial, district, and sub-district hospitals. Although the Kenya National Drug Policy provides that the Kenya Essential Drugs List should be updated at least every two years, the current list was agreed to in 2002 and published in 2003.

[111] Republic of Kenya, Ministry of Health, "Kenya Essential Drugs List," art. 2.1. The Essential Drugs list also states that asprin, paracetamol and ibuprofen should be available in health centers.

[112] WHO, "WHO Model List of Essential Medicines," art. 2.2; WHO, "WHO Model List of Essential Medicines for Children," art. 2.2.

Essential drugs for severe, chronic pain

In Kenya, both dihydrocodeine and pethidine are used more often than oral morphine to treat pain, even when oral morphine is available and would be a better alternative.

WHO recommends avoiding pethidine to treat chronic pain because it can become toxic when used over long periods.[113] It is also weaker and shorter-acting than morphine.[114]

Dihydrocodeine (known locally by the brand name DF-118) is very similar to codeine. Both are too weak to treat severe pain. Yet, even in hospitals where oral morphine is available, many more children are given dihydrocodeine than oral morphine.

Recently published textbooks and medical literature recommend against giving codeine or dihydrocodeine to children.[115] Due to genetic differences, many patients find them ineffective, while for others, especially children, who have small body masses, there is a risk of overdose. This risk can be avoided by administering an equivalent dose of morphine instead.[116] WHO is currently developing treatment guidelines for chronic pain in children and is considering whether codeine should be removed from its pain relief ladder, and replaced with tramadol or a low dose of oral morphine.[117]

Kenya should monitor these developments and ensure that health care workers have up-to-date education about the relative merits of these pain medicines. Kenya should also ensure that oral morphine is always available as an alternative to dihydrocodeine and pethidine for the treatment of children's chronic pain.

The Chilling Effect of Kenya's Narcotics Law

Current legislation on opioids in Kenya is perceived by many health care workers as a prohibition on morphine, and has contributed to under-treatment of pain with opioids.

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[113] World Health Organization, *Cancer pain relief and palliative care in children*, p. 31.

[114] World Health Organization, *Cancer pain relief,* p. 24.

[115] Friedrichsdorf SJ, Kuttner L, and Karl H, "Pharmacological Methods to Relieve Pain," in Kuttner L. (ed), *A Child in Pain* (2nd ed), (Bethel: Crown House Publishing, 2010) pp. 221-64; Stefan J. Friedrichsdorf, "Cancer Pain Management in Children," in Paul Farquhar-Smith, Tim Wigmoreand Colm Irving (eds), Anesthesia, *Intensive Care and Pain Management for the Cancer Patient*, (Oxford: Oxford University Press, 2010).

[116] Codeine and dihydrocodeine are metabolized to morphine in the body. Genetic differences mean that some people metabolize very little codeine to morphine, resulting in ineffective pain relief. Other people metabolize more codeine to morphine than would usually be expected, which can result in overdose and has caused child deaths. D.G. Williams, A. Patel and R.F. Howard, "Parmacogenetics of codeine metabolism in an urban population of children and its implications for analgesic reliability," *British Journal of Anaesthesia*, vol. 89, no. 6 (2002), pp. 839-45; Catherine Ciszkowski, "Codeine, Ultrarapid-Metabolism Genotype and Postoperative Death," *New England Journal of Medicine* , vol. 8, no. 36 (2009).

[117] WHO, "Scoping Document for WHO Treatment Guidelines on Chronic Pain in Children," http://www.who.int/medicines/areas/quality_safety/Scoping_WHOGuide_chronic_pain_children.pdf (accessed April 20, 2010), pp. 5-6.

Kenya's 1994 Narcotic Drugs and Psychotropic Substances Control Act (Narcotic Drugs Act) regulates morphine and other opioid pain medicines. Illicit possession of these substances is an offence punishable by life imprisonment and a fine of up to one million Kenyan shillings (KSh) (US$12,256).[118] The act contains exceptions for medical use, allowing medical practitioners and pharmacists, as well patients, to handle, prescribe and possess the medicines. Hospices need to obtain a license to stock morphine, and all health facilities must account annually for how they used the morphine that they purchased. The Act, however, provides no further guidance regarding lawful possession of controlled medicines by health care workers and their patients.[119] A law on "medicinal use of dangerous drugs," envisioned by the 1994 Kenya National Drug Policy, has never been enacted.[120] The Narcotic Drugs Act stipulates that medical practitioners who are convicted under the Act may lose their medical licenses in addition to facing criminal penalties.[121]

The harsh punishments contained in the Act and the lack of clarity around appropriate prescription procedures mean that many health workers in Kenya are afraid of using opioid medications, a problem that the Kenyan Pharmacy and Poisons Board has recognized:

> [D]ue to the punitive nature of the 1994 Act, most providers have shied away from selling opioids.[122]

Although no doctor interviewed by Human Rights Watch was aware of any prosecutions under the Narcotic Drugs Act, several said that misperceptions about drug control laws, fear of legal sanction, and continued reference to opioid pain medicines as "dangerous drugs" deter their prescription.[123] While doctors prescribing morphine recognized the importance of

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[118] Narcotic Drugs and Psychotropic Substances Control Act, Laws of Kenya Cap. 245 (Narcotic Drugs Act), sec. 3. The maximum penalty for possession solely for personal consumption is imprisonment for 20 years. A fine equal to three times the market value of the controlled drug may be imposed if that amount is greater than 1 million Kenyan Shillings. Narcotic Drugs Act, sec. 3(2)(b). At the time of writing, one US dollar was worth 81 Kenyan Shillings.

[119] Ibid., sec. 3(3).

[120] Republic of Kenya, Ministry of Health, "The Kenya National Drug Policy," art. 8. The prescription, supply and dispensing of all medicines is further regulated by the Pharmacy and Poisons Act, *Laws of Kenya*, Chapter. 244, 1957 http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (accessed March 30, 2010).

[121] Narcotic Drugs Act, sec. 15.

[122] Cited in Richard Harding, et al., "Pain Relieving Drugs in 12 African PEPFAR Countries," January 2007, http://www.theworkcontinues.org/document.asp?id=87&pageno= (accessed March 30, 2010), p. 30.

[123] Human Rights Watch interviews with doctors specialized in palliative care and pain treatment, February and March 2010; Human Rights interview with Regina Mbindyo, WHO Medicines Officer, Nairobi, March 8, 2010. The Narcotic Drugs Act replaced the now-repealed Dangerous Drugs Act, Laws of Kenya, Chapter 245, 1933 (repealed) http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (accessed March 30, 2010), known as the 'DDA.' An officer of the Kenyan Pharmacy and Poisons Board told Human Rights Watch that, in the absence of a law on the medicinal use of opioids, the Board continues to apply the rules that were in effect under the DDA. Human Rights Watch interview with Dr. Mikal Ayiro, Pharmacy and Poisons Board, March 3, 2010.

careful procedures for preventing its diversion to illicit use, at least one doctor, who was not in the palliative care field, perceived morphine as a medicine that is "hard to get" as a result of these regulations.[124]

The INCB has stated that health professionals should be able to prescribe and dispense opioids "without unnecessary fear of sanctions for unintended violations."[125] The Commission on Narcotic Drugs, the body of states that are parties to the UN drug conventions, recently passed a resolution calling upon states to "identify the impediments in their countries to the access and adequate use of opioid analgesics for the treatment of pain and to take steps to improve the availability of those narcotic drugs for medical purposes," including by "educat[ing] regulators and health-care professionals."[126]

Procurement and Cost of Morphine as Access Barriers

Lack of Central Procurement of Oral Morphine

The government has failed to centrally procure oral morphine as it does other drugs. This makes access to the drug more difficult.

The Kenya Medical Supplies Agency (KEMSA) procures medicines for all public health facilities. As mentioned above, under Kenya's National Drug Policy and Essential Drugs List, oral morphine should be available in all district, provincial, and national hospitals.[127] However, KEMSA does not currently procure oral morphine tablets or powder for oral solution.[128]

Hospitals may independently procure medicines from private suppliers, but this requires finding a supplier, negotiating terms, and paying for the medicines using funds raised from

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[124] Human Rights Watch interview with a pediatrician A, Nairobi, March 3, 2010; Human Rights Watch interview with Dr. John Weru, February 25, 2010; Human Rights Watch interview with Hellen Karyuki, Kenyan Association for the Study of Pain, February 25, 2010.

[125] INCB, *Demand for and Supply of Opiates for Medical and Scientific Needs,* E.89.XI.5 (New York: United Nations, 1989), p. 15.

[126] UN Commission on Narcotic Drugs, "Promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse," Resolution 53/4, E/CN.7/2010/18.

[127] Ibid., art. 2.2. Injectable pethidine and dihydrocodeine tablets are also listed as essential drugs for sub-district hospitals. Although the Kenya National Drug Policy provides that the Kenya Essential Drugs List should be updated at least every two years, the current list was agreed to in 2002 and published in 2003.

[128] These drugs are not the only drugs on the list that KEMSA does not procure. Republic of Kenya, Ministry of Health, "The Kenya National Drug Policy"; Human Rights Watch email correspondence with public relations officer, KEMSA, April 27, 2010.

patient fees. It is not surprising that public hospitals—which are short-staffed and financially overextended—rarely choose to procure oral morphine privately.[129]

KEMSA maintains that it does not provide oral morphine because there is little demand for it.[130] But a demand-driven approach is wrong for medicines that are classified as essential. Essential drugs must always be available, and if there is little demand—as in Kenya—the government has an obligation find out why this is the case and address the problem. The current system creates a vicious cycle: because KEMSA does not provide oral morphine, hospitals must purchase it out of their own funds and are therefore less likely to use it; KEMSA interprets this as low demand and a reason not to procure oral morphine.

The failure to include oral morphine in the central procurement scheme may also inflate its cost as it discourages public health care institutions from procuring morphine and leaves individual hospitals to negotiate their own terms with the private supplier.

Bulk procurement of oral morphine by KEMSA could increase the total use of the medicine and allow for centralized price negotiations. The government could explore procuring oral morphine from a not-for-profit supplier. In Uganda, for example, the ministry of health commissioned a charitable procurement and manufacturing facility to produce morphine solution to be distributed to hospitals, health centers and palliative care providers, which has resulted in a considerably lower cost of morphine than in Kenya.[131]

Cost of Morphine

The Kenyan government has an obligation to explore ways to ensure that basic oral morphine is available at low cost to people who need pain treatment. Morphine can be produced at a very low price. For example, the Indian pharmaceutical company Cipla sells morphine tablets locally at US$1.70 per gram.[132] In Uganda, a non-profit organization imports

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[129] Human Rights Watch telephone interview with Laborex salesman, March 4, 2010; Human Rights Watch email correspondence with public relations officer, KEMSA, April 27, 2010.

[130] Together with the Ministry of Medical Services and the Ministry of Public Health and Sanitation, KEMSA determines which medicines to procure by annually assessing which medicines are in the greatest demand. A standard order form is then created, which hospitals use to procure medicines from KEMSA. Oral morphine is does not currently appear on the form and thus may not be obtained from KEMSA.

[131] Vanessa Adams, *Access to pain relief – an essential human right* (London: Help the Hospices, 2007), p. 37.

[132] Scott Burris and Corey S. Davis, "A Blueprint for Reforming Access to Therapeutic Opioids: Entry Points for International Action to Remove the Policy Barriers to Care" (Centers for Law and the Public's Health: A Collaborative at the Johns Hopkins and Georgetown Universities, 2008), p. 18.

morphine powder and sells it for $1.72 per gram.[133] Based on this price, the cost of 90 days of treatment for an adult cancer or HIV patient would be about $11.50.[134]

But the price of morphine is higher in Kenya. The morphine powder used in Kenya today is imported by Laborex, a UK-based pharmaceutical company, which sells it to both public and private hospitals and hospices for 292KSh ($3.57) per gram.[135] To encourage its use, Laborex currently sells morphine powder to "needy" private hospices at the lower price of 200KSh ($2.45) per gram. Even so, staff at the Kisumu Hospice said that morphine powder is a significant expense that the hospice sometimes struggles to meet, resulting in pressure to use less.[136]

At present, Kenya, which does not generally tax medicines, imposes a 16 percent import tax on morphine powder, because it is classified as a "raw product." This makes Kenya one of the few countries in the world to tax morphine.[137] At the urging of the Kenyan Hospice and Palliative Care Association, the minister for medical services has written to the minister for finance requesting that the tax be removed, and the request is currently under consideration.[138]

Poor Availability of Medicines for Neuropathic Pain

Some children suffer from neuropathic pain, caused by dysfunctional or damaged nerves, as a side effect of ART or tuberculosis medication, or as a symptom of HIV or cancer.[139] While most children with neuropathic pain get significant relief if they are given morphine or other opioids, about one-third of children need other medicines—such as gabapentin or amitriptyline—to get any relief for their neuropathic pain.[140] Globally, these medicines are

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[133] Human Rights Watch email correspondence with Dr. Anne Merriman, April 8, 2010.

[134] This calculation is based on a relatively high need of 75 mg of morphine per day. Kathleen M. Foley et al., "Pain Control for People with Cancer and AIDS".

[135] Human Rights Watch telephone interview with Laborex salesman, March 4, 2010.

[136] Human Rights Watch interview with palliative care nurses, Kisumu Hospice, March 2, 2010.

[137] Human Rights Watch interview with Dr. Martha Maurer, Pain and Policy Studies Group, WHO Collaborating Center for Policy and Communications in Cancer Care at the University of Wisconsin, January 26, 2010.

[138] Human Rights Watch interview with Dr. Zipporah Ali, National Coordinator, KEHPCA, February 24, 2010.

[139] Human Rights Watch interview with a pediatrician B, New Nyanza General Hospital, Kisumu, March 2, 2010.

[140] Although neuropathic pain is difficult to treat and more research is needed into which medicines work best, medicines commonly used to treat neuropathic pain include amitriptyline and gabapentin. Amery, *Children's Palliative Care in Africa*, p. 118; Stefan J. Friedrichsdorf and Tammy I. Kang, "The Management of Pain in Children with Life-limiting Illnesses," *Pediatric Clinics of North America*, vol. 54 (2007), p. 660.

not always available in formulations appropriate for children.[141] In Kenya, public health facilities often lack any drugs for neuropathic pain.

In our research, we came across a number of cases where pain could not be treated adequately because of the absence of appropriate drugs. For example, at one orphanage, several children suffered from severe HIV-related pain in their hands and feet. The head of the orphanage complained that gabapentin, a medicine commonly used to treat nerve pain, was too expensive for the orphanage to purchase.[142]

Health Workers: Lack of Palliative Care Training and Skills

In Kenya, lack of training about palliative care among health care workers is one of the causes of the dearth of services in this field. Health care workers do not always know how to assess and treat pain and other symptoms. They are often afraid of morphine because of unfounded fears about addiction and have misconceptions about palliative care.[143] The lack of training results in poor medical practice, such as insufficient pain assessment and treatment, and poor communication with child patients and their families.

Under international law, governments are obliged to provide health education for the community and appropriate training for health personnel.[144] WHO has stressed that "education in pain relief and palliative care must be an essential component of training for all health workers who may be expected to treat patients with advanced chronic illness," and that educational programs for the public, health care personnel and regulators are also necessary.[145]

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[141] Human Rights Watch interview with South African experts on pediatric palliative care, Nairobi, March 5, 2010.

[142] Human Rights Watch interview with head of orphanage, Nairobi, March 3, 2010.

[143] There is an important distinction between physical dependence and addiction. Physical dependence is a side effect of chronic pain treatment with opioids, which is addressed by gradually reducing the dose when pain treatment is no longer needed. According to WHO, "Fear of what is commonly thought of as opioid addiction is one of the principal reasons for children with severe cancer pain not receiving adequate analgesia. This fear has been greatly exaggerated. 'Addiction' occurs when individuals are overwhelmingly involved in obtaining and using a drug primarily for its euphoric effects. This is not a problem in children with cancer who receives opioids for pain control." WHO, *Cancer Pain Relief and Palliative Care for Children*, p. 43.

[144] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para. 43.

[145] WHO, *National Cancer Control Programs,* p. 87; WHO, *Cancer Pain Relief,* p. 42.

Lack of Training among Health Workers

Doctors and Nurses

Kenyan medical schools address palliative care only briefly, and the large majority of Kenyan doctors have little knowledge or experience in this area.[146] Pain management is dealt with briefly in the curriculum on management of chronic disease, but with little attention to treating severe pain with opioids. The main message to medical students is that the cause of the pain must be treated, not the pain itself; pain caused by medical procedures is considered unavoidable.[147] A lecturer and pain specialist at Nairobi Medical School told us:

> [P]art of the training was to give these drugs [opioids] to the terminally ill. So as long as you don't have a terminally ill patient, it doesn't even cross your mind that you can prescribe such drugs…. We are all trained that opioids are given [only] to the terminally ill because of addiction. The addiction aspect was really over-emphasized.[148]

Although medical schools have recently ceased telling students that opioids are only for the terminally ill, these attitudes persist. Training for nurses on palliative care is slightly better, but not sufficient, according to the Kenyan Hospices and Palliative Care Association (KEHPCA).[149]

The general reluctance of health care workers to treat pain with morphine or even weaker opioids, and to provide palliative care, is magnified when it comes to children. There are differences in palliative care for adults and children: the spectrum of diseases encountered, the doses and formulations of pain medicines, and the psychological, social, and cultural issues that come up in communication with patients' families.[150] Nonetheless, in Kenya, there is no specific training on palliative care for children. As a result, there are no pediatric palliative care specialists and pediatricians have no specialized knowledge of pain treatment and palliative care for children.

As almost every doctor and nurse will encounter adults and children with life-limiting illness and pain, the curriculum for medical and nursing students should contain training on pain

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[146] Human Rights Watch interview with Prof. Were, head of the Kenya Pediatric Association, March 3, 2010.

[147] Human Rights Watch interview with Dr. Esther Munyoro, palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010.

[148] Human Rights Watch interview with Dr. Hellen Kariuki, Nairobi, February 25, 2010.

[149] Human Rights Watch interview with David Musyoki, KEHPCA, Nairobi, February 24, 2010.

[150] Amery et al., "The Beginnings of Children's Palliative Care," *Journal of Palliative Medicine*, pp. 1015-16.

treatment and palliative care, including pediatric pain treatment and palliative care. Efforts to improve the curriculum are currently underway at Nairobi Medical School and at one nursing school in Nairobi, and will hopefully bear fruit soon.[151]

Continuing medical education is an important way to educate doctors who have already completed their basic education, especially because junior doctors learn as much from training under more senior doctors as they do from their formal studies. Kenyan doctors are required to undertake continuing professional development annually.[152] KEHPCA offers palliative care workshops and other short training sessions in which palliative care specialists give lectures on the topic to other health workers. The coordinator of KEHPCA and the nurses at Kisumu Hospice, who give similar training sessions, told Human Rights Watch that they usually lead to increased referrals to hospices and palliative care units.[153]

Doctors and nurses working in palliative care sometimes get additional vocational training while working in Kenya or abroad. KEHPCA offers courses of varying length, and Kenyatta National Hospital and Nairobi Hospice offer one week courses for health workers. Nairobi Hospice also offers a diploma in cooperation with a British university, and Kenyan palliative care specialists have undertaken other advanced courses offered by universities in Uganda, South Africa, and the UK.[154] Such training is highly valuable and has helped increase the capacity of Kenya's palliative care specialists.

Community Health Workers

Community health workers do not have the expertise to prescribe strong pain medicines, but with basic training, they can assess pain, including in children, and refer patients who need opioids to a service that prescribes them. Community health workers can also play an important role in monitoring patients to ensure that they are taking opioid medicines correctly, and administering them to patients who are not able to do so themselves, as they often do with ART. At Kisumu Hospice, nurses teach individual community health workers to

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[151] Human Rights Watch interview with Dr. Zipporah Ali, National Coordinator, KEHPCA, Nairobi, February 24, 2010.

[152] Medical Practitioners and Dentists Board, "CPD Guidelines," January 2010, http://www.medicalboard.co.ke/index.php?option=com_content&view=article&id=24&Itemid=21 (accessed July 2, 2010).

[153] KEHPCA, "Annual Report 2008," pp. 8-9; Human Rights Watch interview with palliative care nurses, Kisumu Hospice, March 2, 2010.

[154] KEHPCA, "National Participants Manual for Health care Providers," October 24, 2008; KEHPCA, "Annual Report 2008"; Education, Hospice Africa Uganda, "Bachelor's Degree in Palliative Care (Distance Learning)," undated, http://www.hospiceafrica.or.ug/index.php?mod=article&cat=educ&article=37 (accessed March 25, 2010); Nairobi Hospice, Oxford Brookes University, "Diploma in Higher Education in Palliative Care DipHE," undated, http://shsc.brookes.ac.uk/images/pdfs/courses/postqualifying/long_courses/palliative-nairobi_091222.pdf (accessed March 25, 2010); School of Health and Social Care, Oxford Brookes University, "Palliative Care, Nairobi Hospice," undated, http://shsc.brookes.ac.uk/courses/post-qualifying/labc/palliative-care-nairobi-hospice (accessed March 25, 2010).

do this when they know that a patient prescribed morphine by the hospice will be in their care, but this practice is rare.[155] The head of a community-based organization in a slum providing home-based care for people living with HIV said she had never heard about morphine until Human Rights Watch visited, and added:

> We hope that in the future the government or even partners or donors can train more caregivers in palliative care because we are not getting the training … If we all get that palliative care training, I think [we] can really support [people] and give hope to many people who are hopeless, especially if they … have terminal diseases in the community.[156]

Small numbers of community health workers have been trained in palliative care for people living with HIV. Their training has focused on basic symptom relief and counseling, and other aspects of palliative care that community health workers can provide, and has sensitized them to the importance of referrals to higher-level health facilities.[157] However, such training is still relatively rare and does not focus on assessing pain or administering opioid medicines. Community health workers receive almost no training on palliative care for children or for people with diseases other than HIV.

Lack of Skill in Assessing and Treating Pain

Assessing Pain

Assessing pain in children can be difficult when they are too young or otherwise unable to describe how they feel. Assessment is also difficult in children who have suffered chronic pain all their lives and who do not know a pain-free state. Some children do not want to talk about pain, one nurse told us, because they believe that "if you can bear pain, you can be strong."[158]

Health workers in Kenya are not trained to assess pain in children, and when they examine a patient, they do not regularly do it. Generally, doctors do not communicate much with

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[155] Human Rights Watch interviews with community health workers in Mathare, Kisumu and Nyangoma, February and March, 2010.

[156] Human Rights Watch interview with Ann Wanjiru, head of GROOTS Mathare Mothers Development Centre, Mathare, February 26, 2010.

[157] Human Rights Watch interviews with community health workers, Mathare, Nairobi, February 26, 2010, and Nyangoma, Bondo district, February 28, 1010. Such trainings also cover aspects of home-based care, such as the treatment of wounds and bedsores.

[158] Human Rights Watch interview with palliative care nurse B, Kenyatta National Hospital, Nairobi, February 24, 2010.

patients, and even less so with child patients.[159] With regards to older children and adults, a pain specialist told us:

> What I see as the biggest problem in managing pain in this country is that many [patients] do not know they need to tell us about pain. But if we sensitize them by asking them, "Are you in pain?" then … tomorrow they will come back more comfortable to report that, "Actually, this place is painful."[160]

This problem was illustrated by 12-year-old Beatrice A., who since June, 2009, had been suffering from a painful and itchy skin condition. The condition initially caused parts of her flesh to flake off and made it especially painful to bathe. Beatrice had visited a dispensary, a private clinic, and another health facility in Nyanza province. At each facility, health workers treated Beatrice's condition but never asked her whether it was painful or offered her any pain treatment.[161]

Treating Pain with Opioids

As a result of poor pain assessment and unwarranted fear of prescribing opioids, health workers often fail to treat severe pain with opioids even when they are available and a child is evidently in pain.

Some doctors at Kenyatta National Hospital and New Nyanza General Hospital treat child cancer patients with dihydrocodeine for short periods, and then withdraw the medicine for a period, due to its side effect of constipation, despite the WHO recommendation that pain medicines be administered at regular intervals around the clock.[162] It should be common practice to treat constipation with a laxative, not by withdrawing pain treatment.[163] This happened to three-year-old Alex K. at Kenyatta National Hospital, who suffered from leukemia.[164] Similarly, in New Nyanza General Provincial Hospital, a nurse explained that Thomas N., age 12, was given dihydrocodeine intermittently, and otherwise given diclofenac,

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[159] Human Rights Watch interview with Prof. Nduati, Nairobi, February 24, 2010.

[160] Human Rights Watch interview with Dr. Hellen Kariuki, Nairobi, February 25, 2010.

[161] Human Rights Watch interview with Beatrice A., age 12, and her grandmother, Nyangoma, Bondo district, February 27, 2010.

[162] WHO, "WHO's pain ladder."

[163] Friedrichsdorf and Kang, "The Management of Pain in Children with Life-limiting Illnesses," *Pediatric Clinics of North America,* p. 659.

[164] Human Rights Watch interview with father of Alex K., age 3, Kenyatta National Hospital, Nairobi, March 5, 2010. Alex's father was told that his son was given DF-118 on and off because of constipation.

a weaker pain medicine.[165] Thomas complained of strong headaches during the treatment with diclofenac. His mother explained:

> [My son] has a tumor on the belly… Here [at New Nyanza General Hospital]… he still suffers a lot of pain. Even now, he is in pain. He has a terrible headache. This morning he was given medicine [diclofenac] against the headache but it did not get better.[166]

Several doctors told us that when they prescribe morphine to children, nurses sometimes refuse to administer it.[167] A doctor who treats childhood cancer found that children are at a particular disadvantage:

> People have no problems with relieving pain in adults with morphine, but when it comes to children, there is always some reservation. Putting a child on morphine is always a big issue … Morphine is underutilized.[168]

Case Study: Kenyatta National Hospital

Kenyatta National Hospital is a national teaching and research hospital, and by far the most important public health facility in Kenya. It has a capacity of 1,800 beds and treats about 89,000 inpatients and 600,000 outpatients a year.[169]

During our visit, there were an estimated 120 children with cancer on various pediatric wards, and none was being treated with morphine. Only one 16-year-old girl in an adult oncology ward—Judith, whose case is described above—received morphine.[170]

Only one of the wards—the pediatric oncology ward, for 28 children—is specialized in childhood cancer. Some nurses on the pediatric oncology ward have received training in palliative care and have experience treating severe pain and dealing with the stress of

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[165] Human Rights Watch interview with nurse on pediatric oncology ward, New Nyanza General Provincial Hospital, Kisumu, March 1, 2010.

[166] Human Rights Watch interviews with Thomas N., age 12, his mother, and the nurse in charge, New Nyanza General Hospital, Kisumu, March 1, 2010.

[167] Human Rights Watch interview with Dr. Esther Munyoro, palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010; Human Rights Watch interview with Dr. John Weru, February 25, 2010.

[168] Human Rights Watch interview with a doctor treating children with cancer A, February 25, 2010.

[169] Ministry of Medical Services, "Kenyatta National Hospital," http://www.medical.go.ke/index.php?option=com_content&task=view&id=39 (accessed May 18, 2010).

[170] Human Rights Watch interview with Dr. Esther Munyoro, head of the palliative care unit, Kenyatta National Hospital, Nairobi, March 5, 2010.

childhood cancer. But even those nurses are reluctant to give morphine to children. One nurse told us that she only refers children to the palliative care unit of her hospital when "the child is very sick, not responding to pain treatment, and when the child is just crying from pain."[171] Her ambivalence became evident when she said to us on one day, "Giving morphine is OK," and on another, "We don't like to give morphine."[172] Some nurses also fear that morphine will cause respiratory distress, especially in children.[173]

As a result, children are referred late, if at all, to the palliative care unit that prescribes morphine. The head of the palliative care unit told us:

> We often get sent the patients too late: they are close to death or nothing can be done. We need to find a way to make sure patients are referred earlier.[174]

Moreover, due to overcrowding, the majority of children with cancer are not concentrated in pediatric cancer wards, but dispersed among eight other wards.[175] These children do not benefit from special attention from nurses who focus on caring for children with cancer. One doctor observed that nurses in the other wards sometimes do not administer morphine as prescribed, "because they are afraid … they rarely handle opioids." He also found that children with cancer get less pain treatment in the other wards due to staff shortages and lack of attention to children's pain. He told us:

> Children must wait longer for pain treatment. On [these other] wards, understaffing and lack of communication between staff are problems. The nurses rotate and this delays administration of drugs. A doctor might prescribe a drug, but it might take two days for it to come. There is a lack of vigilance. The nurses are not looking for pain. Pain should be added to the charts that the nurses fill in when they first see a patient, as a way of institutionalizing pain treatment, by asking the question.[176]

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[171] Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25, 2010.

[172] Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25 and March 3, 2010.

[173] Human Rights Watch interview with nurse, Kenyatta National Hospital, Nairobi, February, 25, 2010.

[174] Human Rights Watch interview with Dr. Esther Munyoro, Kenyatta National Hospital, Nairobi, February 24, 2010.

[175] They are distributed among four pediatric wards, as well as wards for dental and facial diseases; ear, nose, and throat diseases; and eye diseases.

[176] Human Rights Watch interview with a doctor treating children with cancer B, February 26, 2010.

Treating HIV-Related Pain

Health workers tend to associate pain only with certain diseases, such as cancer, and not with others, including HIV, and consequently often fail to assess pain in patients with these diseases. Some pediatricians consider pain in children on ART "not a big issue."[177] However, studies have shown that children and adults living with HIV—including those on ART—can experience moderate to severe pain, including neuropathic pain, and have significant needs for palliative care.[178] The head of the hospice in Nairobi remarked:

> Patients with HIV also have severe pain, especially the type of pain called neuropathic. Its control is poor, but I believe the clinicians don't know that patients with pain who are HIV-positive also need a palliative care team to take care of their pain.[179]

The need for comprehensive palliative care to be integrated into the HIV response was demonstrated by stories of children who were receiving ART but had many untreated symptoms, including pain. A community health care worker in Kisumu, Nyanza province, told us about five-year-old Douglas O., an orphan whose only caregiver was his adolescent sister. Douglas was on ART but his sister did not give the medicine to him regularly. He was very sick:

> The body and his wounds were very painful and eating was very difficult. He would refuse food and cry. Blood would come out of his mouth when we washed it…. He was in pain … it would hurt him to bathe. He would cry because of wounds and peeling off of skin.[180]

Other community health workers and orphanage staff related similar experiences of helplessness in the face of severe pain in an HIV-positive child.[181]

A palliative care doctor told us about difficulties in reaching out to HIV services, which operate somewhat separately from the rest of the health system:

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[177] Human Rights Watch interview with a pediatrician C, Nairobi, February 24, 2010.

[178] Selwyn and Forstein, "Overcoming the false dichotomy of curative vs. palliative care." Collins and Harding, "Improving HIV management in Sub-Saharan Africa: How much palliative care is needed?" Family Health International, "Integrating palliative care into primary HIV care services." For more details see above, Chapter I.

[179] Human Rights Watch interview with Dr. John Weru, February 25, 2010.

[180] Human Rights Watch interview with community health worker, Kisumu, March 1, 2010.

[181] Human Rights Watch interview with community health workers, Mathare, Nairobi, February 26, 2010; Human Rights Watch with staff member of orphanage, Nairobi, March 4, 2010.

> We should be looking after more children with HIV. But it is hard to penetrate this area. The CCC [Comprehensive Care Centre providing HIV care] only brings patients when they are literally screaming.[182]

Lack of Training among Pediatricians

Not a single Kenyan pediatrician has received training on palliative care at the diploma level, and very few have received any training beyond limited instruction during medical school. There are also very few pediatricians with specialized knowledge of childhood cancer, which is often treated by hematologists who have no pediatric background.[183]

One reason for this is that palliative care is widely misunderstood as a replacement for curative treatment, and many pediatricians see it as part of their ethic to fight for a child's life and not give up. A leading Kenyan pediatrician expressed her concern that palliative care would become a "dump basket" for children who should get curative treatment. She also complained that "there has been too much home-based care, it is too easy."[184] Another pediatrician said that:

> Getting children on treatment is a battle. Palliative care could become the easy way out. "Palliative" suggests you are not giving them treatment.... People think here that it teaches a message that you don't want to convey.[185]

Lack of Health Worker Skills in Communicating with Child Patients and Parents

Parents and children living with life-limiting disease have a great need to know what is happening to them and to express their worries and fears. Effective communication and psychosocial support is a key component of palliative care.

WHO emphasizes the importance of psychosocial support for children and their families.[186] Under international law, the right to health care includes mental health care and the right to information about health care.[187] Children have a right to age-appropriate information about

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[182] Human Rights Watch interview with Dr. Esther Munyoro, Kenyatta National Hospital, Nairobi, February 24, 2010.

[183] Human Rights Watch interview with Prof. Fred Were, head of the Kenya Pediatric Association, March 3, 2010.

[184] Human Rights Watch interview with Prof. Ruth Nduati, Nairobi, February 24, 2010.

[185] Human Rights Watch interview with pediatrician B, New Nyanza General Hospital, March 2, 2010.

[186] WHO, *National Cancer Control Programs*, p. 85.

[187] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, para 22.

their health conditions, to participate in decision making regarding their own health care, and to psychological support. However, at present, health workers communicate very little about children's illnesses and their consequences to caregivers and to the children themselves. As a result, parents and children are left alone with their worries and fears.

Communication with Parents

Many doctors communicate poorly with parents about their child's diagnosis, treatment, and prognosis, and the uncertainty caused by this lack of communication can create additional emotional turmoil for the child and family. Parents interviewed for this research showed varying degrees of understanding regarding their children's illnesses.

According to an experienced child oncologist, many doctors do not tell parents when their child has terminal cancer.[188] One doctor in New Nyanza General Hospital told a woman that her daughter's disease "can only be cured by luck," which left her confused as to whether there was hope or not.[189] At the same hospital, the father of four-year-old Florentine P. complained that he did not know who the child's doctor was. He also mistakenly assumed that her upcoming biopsy was intended to treat the disease.[190]
When James Nyaga took his son, age three, to Kenyatta National Hospital, doctors did not tell him what disease they had diagnosed. So he searched the Internet, using several terms the doctors used, and realized that his son had cancer (a primitive neuroectodermal tumor). He commented:

> I couldn't understand why nobody would tell me about my own child. I think that they [the doctors] think that I wouldn't understand.[191]

Nyaga's son was treated with chemotherapy and subsequently discharged and cared for at home. Although the medical staff did not directly tell Nyaga that his son's disease was incurable, that was his understanding. A few months after Human Rights Watch spoke with Nyaga, we were informed that his son had died.

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[188] Human Rights Watch interview with Dr. Juliana Otieno, New Nyanza General Hospital, Kisumu, March 1, 2010.

[189] Human Rights Watch interview with mother of Betty, age ten, New Nyanza General Hospital, March 1, 2010.

[190] Human Rights Watch interview with father of Florentine, age four, New Nyanza General Hospital, March 1, 2010.

[191] Human Rights Watch interview with James Nyaga, founder of Hope for Cancer Kids, Nairobi, February 24, 2010. James Nyaga founded a support group for parents of children with cancer, which has since become an NGO, called Hope for Cancer Kids.

In Kenyatta National Hospital, some parents have weekly "counseling" sessions with medical doctors. During these sessions, doctors provide medical information. They rarely address psychological, emotional, and social issues.[192]

Some private facilities, including church-based health facilities, offer professional psychosocial support. For example, Pandipieri is a Catholic community health center in Kisumu that has a child counseling program and trains bereavement counselors.[193] But public hospital staff must also communicate clearly and effectively to children and their parents about the illness and offer support as families manage their emotions.

Communication with Children: "You need to break the conspiracy"

All sick children need to communicate through language and play to cope with the discomfort of disease, the daily routines of illness, medical treatments, and the threat of death.[194]

But health workers are not trained to elicit such communication, or even to discuss the basic facts of the disease with children and their parents; most rarely make emotional support for sick children a priority.[195] It is emotionally difficult for health care workers (and for parents) to disclose to children that their illness is serious or terminal, and many avoid it completely. Sometimes parents explicitly ask health workers not to disclose information to the child.[196] This is especially true of HIV/AIDS. Because of the continuing stigma, many parents conceal from their child—even as the child approaches adolescence—that he or she is HIV positive.[197] The lack of communication about the disease leaves many children anxious and fearful. Hospitals provide no counselors, psychologists, or social workers for children with chronic diseases.

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[192] Human Rights Watch interview with James Nyaga, founder of Hope for Cancer Kids, Nairobi, February 24, 2010; Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25, 2010.

[193] Human Rights Watch interview with Pandipieri trainer, Kisumu, February 26, 2010. Another example is psychosocial support at Nyumbani Children's Home.

[194] Amery, *Children's Palliative Care in Africa.*

[195] Human Right Watch interview with James Nyaga, founder, Hope for Cancer Kids, February 24, 2010.

[196] This happened for example in the cases of Kevin N. and Judith A., whose stories are mentioned above. Human Rights Watch interview with palliative care nurse A, Kenyatta National Hospital, Nairobi, February 24, 2010.

[197] Human Rights Watch, *Letting Them Fail: Government Neglect and the Rights to Education for Children Affected by AIDS*, vol. 17, no. 13 (A), October 2005, http://www.hrw.org/en/reports/2005/10/11/letting-them-fail (accessed March 31, 2010); Human Rights Watch, *In the Shadow of Death: HIV/AIDS and Children's Rights in Kenya*, vol. 13, no.5(A), June 2001, http://www.hrw.org/en/reports/2001/06/02/shadow-death (accessed March 31, 2010).

When doctors do disclose information, they tend to do so very late, after the child has already figured it out, as the head of the palliative care unit in Kenyatta National Hospital explained:

> Children disclose to each other about their diseases. They say "if you are in this ward, you have cancer"... By the time we do [disclose], they already know. You tell the parent first but they don't want to tell the child. Sometimes you need to break the conspiracy.... Sometimes children think they are sick for the wrong reasons.[198]

Some children believe that someone must be responsible for their illness, and need to be told that no one is to blame.[199] Nurses at Kenyatta National Hospital told Human Rights Watch of several children who believed that they were ill or in hospital because they were "bad," or because someone else had brought the illness upon them. One was an 11-year-old girl who had cancer in her leg, and subsequently broke the leg when she fell down. She believed that another family in conflict with her family had done this to her.[200]

Many children miss their parents and siblings terribly because they are far from home. One father described the loneliness of his 11-year-old son Steve K., from Kitui in Eastern province, who was being treated for Non-Hodgkin's lymphoma in Kenyatta National Hospital:

> He is [emotionally] affected. He never went home. He misses home, his siblings, school. He asks when I go home. He cries when I go home [the father lives in the city]. He could feel very displaced.[201]

In one case, Kenyatta National Hospital was treating a terminally ill six-year-old orphan with HIV and cancer from Nyanza province. He expressed the wish to go back to his home area to see his siblings, but his relatives and the nurses did not want this, so he died in Nairobi.[202]

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[198] Human Rights Watch interview with Dr. Esther Munyoro, head of the palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010.

[199] Amery, *Children's Palliative Care in Africa*, p. 13; Human Rights Watch interview with palliative care nurse B, Kenyatta National Hospital, Nairobi, February 24, 2010.

[200] Human Rights Watch interview with palliative care nurse B, Kenyatta National Hospital, Nairobi, February 24, 2010.

[201] Human Rights Watch interview with father of Steve K., age 11, Nairobi, February 25, 2010. Steve's father moved to Nairobi to be with his son in hospital, though he did not stay overnight.

[202] Human Rights Watch interview with Dr. Esther Munyoro, Kenyatta National Hospital, Nairobi, February 24, 2010.

Parents of children with cancer have founded Hope for Cancer Kids, an NGO, with the explicit aim of "trying to look at what the child wants … and turning that into a program."[203]

Parents' and Caregivers' Responsibilities

Attitudes towards Pain and Pain Treatment

Many Kenyan patients do not talk explicitly about pain to health workers, or even to family members. As one doctor put it, people "have been brought up … to believe you should brave it."[204] A palliative care nurse said that her patients often feel they should not talk about pain because others will consider them weak.[205]

Self-treatment is an important part of Kenyan medical culture. People usually deal on their own with common illnesses such as malaria by taking paracetamol or aspirin, for example. Only when an illness is prolonged or very serious do people seek advice from a traditional healer or a medical professional.[206]

Yet many Kenyans are not aware of the existence of stronger pain medicines, and so few people actively seek specialized treatment for severe pain for themselves or their children. There is also little information about hospital- or hospice-based palliative care, and many people are simply unaware of such services. The head of the Nairobi hospice said:

> I think there's that acceptance of pain as a part of an illness.... People don't know and don't believe that someone can be pain free, especially [with] cancer and HIV/AIDS. The society knows that they are painful illnesses, so when you talk about pain, that is normal for that illness.[207]

Under international law, governments have a duty to ensure that people have access to health information, including regarding children's health.[208] Public education about pain medication is one of WHO's key recommendations to improve access to it.

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[203] Human Right Watch interview with James Nyaga, founder, Hope for Cancer Kids, February 24, 2010.

[204] Human Rights Watch interview with Dr. Hellen Kariuki, Nairobi, February 25, 2010.

[205] Human Rights Watch interview with palliative care nurse B, Kenyatta National Hospital, Nairobi, February 24, 2010.

[206] P. Wenzel Geissler et al., "Self-treatment by Kenyan and Ugandan schoolchildren and the need for school-based education," *Health Policy and Planning*, vol. 16, no. 4 (2001), pp.362-71.

[207] Human Rights Watch interview with John Weru, February 25, 2010.

[208] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, paras 11, 22.

Neglect of Children in Need of Palliative Care

Experts on palliative care in Africa have emphasized that because there are many orphans and other vulnerable children, child protection constitutes an important part of pediatric palliative care.[209] As in other African countries, Kenya has a large number of orphans whose parents have died of HIV/AIDS or other causes. Other children are vulnerable because HIV/AIDS or poverty make it difficult for their parents to care for them. Most parents and caregivers do their utmost to look after a seriously ill child. However, some fail to provide medical care even when it is clear that the child needs it.

In some cases, HIV-positive orphans are moved from one relative to the next, or abandoned by relatives altogether.[210] One such case was two-year-old Ann A., an HIV-positive orphan from Nyanza province who had been taken in by the first wife of her deceased father (her mother was his second wife). The woman and her husband looked after Ann for a while, but when she became sick with pneumonia and a skin disease, they decided that they did not want her any more.[211] The girl was taken in by a staff member of an (non-residential) orphan support organization, which provided her with treatment for her pneumonia and skin disease and eventually persuaded her father's former wife to accepted custody of Ann again.

In another case, a boy called Douglas O., whose case is mentioned above, died of an HIV-related disease at the age of five. The same orphan support organization that cared for Ann provided home-based care for Douglas. He was an orphan looked after by his 15-year-old sister. The girl was poor and stayed with a man who took care of her, but refused to look after Douglas. The head of the orphan support organization explained:

> This person didn't want [Douglas] to join them…. Then [the sister] decided to go to her aunt and leave her brother there outside the gate. Because he was crying, the aunt found him and took him in. It took us long to trace [Douglas] … We took the initiative of going to their home…. He was again very down. The husband of the aunt also never accepted him so he was put again in another place. Nobody was giving him proper care. The much we could do was to give food and money to take care. After two days we were told he was dead.[212]

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[209] Amery et al., "The Beginnings of Children's Palliative Care," *Journal of Palliative Medicine*.

[210] Human Rights Watch, *A Question of Life or Death*, pp. 41-45.

[211] Human Rights Watch interview with head of orphan support organization, Kisumu, February 27, 2010.

[212] Human Rights Watch interview with head of orphan support organization, Kisumu, March 1, 2010.

Sometimes, caregivers also deny children access to medical tests or to medicine, even when they are visibly sick. Pain medicines are not even considered. A community health worker in the Mathare slum in Nairobi explained how the father of Josephine W., age nine, reacted to his wife's and daughter's sickness:

> [Josephine] is nine and HIV-positive. She is an orphan and lives with her stepmother…. She is not going to school. She is in a lot of pain. She complains at times of chest pain. Sometimes her whole body is in pain. The girl is on ART, and so is the stepmother. But the father does not want any of this. He has said he will throw the drugs away when he finds them in the house.[213]

As stated above, WHO defines palliative care as "the active total care of the child's body, mind and spirit."[214] For orphans and vulnerable children who have life-limiting disease, palliative care should include child protection. This requires health care workers who are trained in child protection issues, as well as a functioning child protection system.

International and Kenyan laws stipulate that the authorities must take steps to protect children from violence, abuse, and neglect.[215] In Kenya, the Children Act prohibits child abuse and neglect. The Department of Children's Services is responsible for implementing the Act and employs about 320 children officers across Kenya. The Children Act empowers a children officer to take a child in need of protection to a place of safety, or a child in need of medical care to a health institution. In practice, the child protection system is understaffed and weak, and often fails to reach children in need.[216]

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[213] Human Rights Watch interview with community health worker A, Mathare, Nairobi, February 26, 2010.

[214] World Health Organization (WHO), "Palliative care," undated, http://www.who.int/cancer/palliative/en/ (accessed February 12, 2010).

[215] 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, arts. 7, 9(1); The Children Act, sec. 13(1).

[216] Human Rights Watch, *A Question of Life or Death*, pp. 80-83.

Economic Barriers to Pain Treatment and Palliative Care

Health Care Costs

User Fees in Kenya

In Kenya, where around 20 percent of the population survives on less than a dollar per day, cost is a major barrier for children to access health care including pain treatment.[217] While the government has instituted a policy of health services for free for children under five at lower-level health facilities, and at a nominal fee for those over five, these policies are not uniformly implemented. Indeed, the government has conceded that these policies are "not adhered to and clients are still paying for the free services."[218]

The policies also do not cover district, provincial, and national hospitals. At these hospitals, patients have to pay for medicine, tests and treatment, and the bed. At provincial and national hospitals, patients are also charged an admission fee.[219] At Kenyatta National Hospital, children pay 4,000KSh($49.02) for admission, or 8,000KSh ($98.05) for admission if the child is likely to need surgery. A bed costs 400KSh ($4.90) per night. Patients must usually pay for any medicines at the hospital pharmacy, although some drugs might be available in the hospital and administered without fees.[220]
In New Nyanza General Hospital, the situation is slightly better. Child patients pay 200KSh (approximately $2.45) per night for a bed for the first two weeks; after that, the bed does not cost anything, and children under the age of five are not charged a bed fee. There is generally no separate charge for medicines, although there are charges for some disposable equipment.

At New Nyanza General Hospital, chemotherapy is subsidized by a donor, but at other hospitals, its cost is particularly prohibitive.[221] In Kenyatta National Hospital, costs may range from 50,000KSh (approximately $613) to over 500,000KSh (approximately $6,130), depending on the case.[222] For example, 11-year-old Steve K., an inpatient suffering from Non-

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[217] 19.7 percent of Kenyans live on less than $1 per day, (purchasing power parity at international dollar rate, 2005). WHOSIS.

[218] Ministry of Public Health and Sanitation, "Strategic Plan 2008-2012," December 2008, p. 14. This was also found in National Coordinating Agency for Population and Development (NCAPD), Ministry of Health (MOH), Central Bureau of Statistics (CBS), ORC Macro, "Kenya Service Provision Assessment Survey 2004," 2005, http://www.measuredhs.com/pubs/pub_details.cfm?ID=561&srchTp=advanced (accessed March 16, 2010), p.77. The policy requires patients to pay a fee of 10KSh (approx. 0.13 USD) at dispensaries and a fee of 20KSh (approx. 0.26 USD) at health centers. Ministry of Public Health and Sanitation, "Strategic Plan 2008-2012," p. 14.

[219] For an overview of hospital costs in Kenya (excluding drugs and diagnostics), see WHO, "Estimates of Unit Costs for Patients Services for Kenya," http://www.who.int/choice/country/ken/cost/en/index.html (accessed March 25, 2010).

[220] Human Rights Watch interviews with staff and patients at Kenyatta National Hospital, Nairobi, February 2010.

[221] Human Rights Watch interview with Dr. Juliana Otieno, New Nyanza General Hospital, Kisumu, March 1, 2010.

[222] Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25, 2010.

Hodgkin's lymphoma, underwent chemotherapy, radiotherapy, and surgery at a total cost of 448,000KSh ($5,491). His father paid by selling land and asking others for money. He also received some support from the National Health Insurance Fund, but was unable to keep up his contributions. When we met Steve's father, another bill for further treatment was imminent, and he did not know how he would pay.[223]

There is a fee waiver system for destitute patients, but it often fails to function. In some hospitals, patients are detained after they have completed their treatment because they are unable to pay the bill.[224]

The current health insurance scheme, the National Hospital Insurance Fund, mainly insures patients who work in the formal sector, and this excludes the poorest segments of the population.[225] According to one health donor, about 40 percent of Kenyans do not seek health care when they need it because of the cost.[226]

As a result of the complex and sometimes inconsistent user fee policies in the public hospital system, patients sometimes assume that they have to pay for health services even when they should be free or relatively low cost.[227] Outside the public system, fees are even higher and more erratic. About 40 percent of Kenya's health services are delivered by church-based health facilities, which usually charge more than public facilities because they do not receive state subsidies.[228] User fees are significantly higher yet at private, for-profit facilities.

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[223] Human Rights Watch interview with father of Steve K., age 11, Nairobi, February 25, 2010.

[224] Beatrice Gachenge, "KNH ailing from heavy burden of Defaulters," *Business Daily*, August 5, 2009, http://www.businessdailyafrica.com/-/539552/634896/-/item/0/-/6j95vxz/-/index.html (accessed March 18, 2010). GTZ Kenya, "Detention of patients in public hospitals," unpublished document (on file at Human Rights Watch).

[225] Diana N. Kimani, David I. Muthaka and Dminaro K. Manda, *Health care Financing Through Health Insurance in Kenya: The Shift To A National Social Health Insurance Fund*, KIPPRA Discussion Paper Nr. 42 (Nairobi: Kenya Institute for Public Policy Research and Analysis 2004).

[226] Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ), "Strategy for Accessible, Affordable and Quality Health care in Kenya," February 11, 2010, power point presentation (on file at Human Rights Watch). Treatment for certain diseases is free of charge for children and adults alike. This includes anti-retroviral treatment for HIV, treatment of HIV-related opportunistic infections, other sexually transmitted diseases, tuberculosis, and malaria. A. Opwora at al., *Health Policy and Planning* 2010, pp. 1-13. Advance Access published online on March 8, 2010, http://heapol.oxfordjournals.org/cgi/reprint/czq009v1?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=User+charges+in+government+health+facilities+in+Kenya percent3A+effect+on+attendance+and+ percentE2 percent80 percentA6&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT (accessed March 18, 2010).

[227] Human Rights Watch interview with nurse in an HIV clinic, Mathare, Nairobi, August 14, 2008; Consortium for Research on Equitable Health Systems (CREHS), "Reducing User Fees, Implementation challenges and a possible solution," October 2009, http://www.crehs.lshtm.ac.uk/downloads/publications/user_fees.pdf (accessed March 18, 2010).

[228] Human Rights Watch interview with representative of Christian Health Association in Kenya (CHAK), Nairobi, August 20, 2008; Ministry of Public Health and Sanitation, "Strategic Plan 2008-2012," p. 51.

Cost of Pain Treatment and Palliative Care for Children

The cost of pain medicines varies dramatically at different health care facilities, often making the drugs inaccessible to children in need. Most patients are expected to pay for their own medicine, though they are often unable to do so. The cheapest way to treat a child's mild pain is with children's paracetamol tablets. They cost 5KSh (approximately US$0.06) in the Mathare slum, where many inhabitants earn less than 75KSh (approximately $0.92) a day. Many other medicines are more expensive.

One community health worker in the slum explained:

> The big problem is that guardians often can't afford the medicine that is prescribed for the child, so they go on doing what they saw the community health worker do—grind up paracetamol in water and give that to the child.[229]

Dihydrocodeine tablets can be difficult to find in pharmacies and cost 10KSh (approximately $0.12) for a 30mg tablet, the maximum daily dose for a child.[230] A weekly dose would cost 70KSh ($0.86).

Some Kenyan hospices give oral morphine free of charge to destitute patients, but others charge for morphine.[231] A 100ml bottle of morphine costs 100KSh ($1.22) at Kenyatta National Hospital and 500KSh ($6.14) at Kisumu Hospice.[232] For an adult prescribed a typical daily dose of oral morphine, this is a two-week supply;[233] as children typically require a lower dose, proportional to their body weight, this amount would usually, but not always, last longer for a child.[234] In a 2007 survey, five Kenyan hospices that charge patients reported

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[229] Human Rights Watch interview with Ann Wanjiru, head of GROOTS Mathare Mothers Development Centre, Mathare slum, Nairobi, February 26, 2010. Community health workers told Human Rights Watch that they would prefer to give small children syrup pain relievers, which are easier to administer and more reliable than trying to feed children crushed tablets, but syrups are much more expensive—as much as 300KSh for a bottle ($382).

[230] Amery, *Children's Palliative Care in Africa*, p. 389.

[231] Human Rights Watch interview with hospice administrator, St Catherine's Hospice, 4 March 2010; Human Rights Watch interview with Dr. John Weru, March 25, 2010; KEHPCA, Annual Report 2008, p. iii.

[232] Human Rights Watch telephone interview with Dr. Esther Munyoro, Kenyatta National Hospital, Nairobi, March 25, 2010; Human Rights Watch interview with palliative care nurses, Kisumu Hospice, March 2, 2010.

[233] Human Rights Watch interview with Dr. John Weru, March 25, 2010.

[234] Human Rights Watch email correspondence with Dr. Stefan J. Friedrichsdorf, Medical Director, Pain Medicine & Palliative Care, Children's Hospitals and Clinics of Minnesota, March 3, 2010; Amery, *Children's Palliative Care in Africa*, pp. 378 and 399.

that between 50 and 95 percent of their patients could not afford to pay the full fee requested.[235]

Under international law, governments have an obligation to make health care services physically and financially accessible, and also provide information about available services.[236] WHO has noted that palliative care services "cost very little" and has urged countries to make palliative care available, including through low-cost community-based palliative care.

Children as Pawns: Detention of Children Whose Parents Cannot Pay the Bill

When parents cannot pay a child's hospital bill, health care workers sometimes keep the child at the hospital until the bill is settled. The practice of de facto detention is meant to put pressure on the parents to come up with the money. Yet it violates Kenya's obligations under international law, which prohibits the detention of debtors.[237]

In some situations, parents abandon their child at the hospital, due to their inability to pay, negligence, or a mix of both. During a visit by Human Rights Watch to Kenyatta National Hospital, there were four such abandoned children in the pediatric oncology ward. One child's parents had explicitly told the hospital that they were not taking back the child. Another child's parents had initially said they would pick the boy up, but had since failed to respond to phone calls from the hospital.[238] In the Mathare slum in Nairobi, we spoke to a young mother who could not pay her child's hospital bill at Kenyatta National Hospital, and thus had only visited her child once in several months.[239] For these children, the suffering of serious illness is compounded by abandonment by parents unable to pay the hospital's fees.

The new Constitution of Kenya protects the right to freedom and security of the person. It provides that no person shall be deprived of freedom arbitrarily or without just cause, or detained without trial, except in a state of emergency.[240] A person unlawfully detained is

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[235] KEHPCA, Annual Report 2008, p. 5.

[236] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, para. 12.

[237] On the legal analysis of hospital detentions, see Human Rights Watch, *A High Price To Pay: Detention of Poor Patients in Burundian Hospitals*, vol. 18, no. 8(A), September 2006.

[238] Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25, 2010.

[239] Human Rights Watch interview with mother of an abandoned child, Mathare, Nairobi, February 26, 2010; additional information from community health worker B, Mathare, Nairobi, February 26, 2010.

[240] Constitution of Kenya, art. 29. http://www.kenyalaw.org/Downloads/The%20Proposed%20Constitution%20of%20Kenya.pdf, (accessed August 6, 2010). At the time of writing, the new Constitution had been passed at referendum but not yet enacted.

entitled to apply to a court for redress, including compensation.[241] The Constitution further provides that children have the right not to be detained except as a measure of last resort, and for the shortest appropriate period of time, and that the child's best interests are of paramount importance in every matter concerning the child.[242]

Transportation Costs

Many children in severe pain do not receive treatment because their parents or caregivers are unable to pay for transportation to a health facility where opioid pain medicines are dispensed.[243] While most Kenyans live within five kilometers from a dispensary or health center, these facilities are only equipped to diagnose and treat a limited number of common diseases. They generally do not have a doctor on staff and have no laboratories. As a result, sick children are frequently referred to district, provincial, or national hospitals for diagnostic tests and treatment. When children cannot afford to make the trip to a higher-level health facility, they often fail to get any diagnosis, making it impossible to establish what type of treatment they need or treat pain.

This problem was exemplified by the situation of four-year-old Jacob O., suffering from a large painful swelling on his back and buttocks, whose case is described above. Since Jacob's family could not afford to go to the nearest hospital, his mother took him to the local dispensary, where she was referred to the district hospital in Bondo, about 10 kilometers away. The mother lacked the means to travel to Bondo and continued to ineffectively medicate his apparently serious illness with simple pain relievers. Jacob continued to suffer pain which affected his mobility and sleep.[244]

Such situations of continued pain can last for years. Also in Bondo district, we met Rebecca A., whose case is mentioned above. Twenty-year-old Rebecca had been suffering from an undiagnosed illness since she was two years old. Several years ago, Rebecca's mother traveled with her to Bondo District Hospital, where she was told she should get treatment at Nyabondo Mission Hospital in South Nyanza, about 100 kilometers away. The mother could

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[241] Ibid., art. 72.

[242] Ibid., arts. 53(f)(i) and 53(2).

[243] This is also the case for treatment of children living with HIV. Human Rights Watch, *A Question of Life or Death*, pp.50.54; see also Horizons/Population Council, "'If You Build It, Will They Come?' Kenya Healthy Start Pediatric HIV Study: A Diagnostic Study to Investigating Barriers to HIV Treatment and Care Among Children," June 2008, http://www.popcouncil.org/pdfs/horizons/Kenya_PediatricHIVTreatment.pdf (accessed March 17, 2010), pp. 33-34.; A. M. Noor et al., "Defining equity in physical access to clinical services using geographical information systems as part of malaria planning and monitoring in Kenya," *Tropical Medicine and International Health*, vol. 8, no. 10 (October 2003), pp. 917-926.

[244] Human Rights Watch interview with mother of Jacob O., age four, Nyangoma, Bondo district, Nyanza province, February 28, 2010.

not afford the travel and also feared the hospital costs, so she never took Rebecca there.[245] Rebecca endured severe pain and trouble walking for most of her childhood.

Transportation is particularly difficult for parents of children with chronic disease. We interviewed relatives of children who had managed to go to a hospital once to seek treatment, but failed to return for check-ups and additional treatment. As a result, children lived for long periods with undertreated pain.[246] Children with cancer are sometimes discharged between cycles of chemotherapy, and some do not come back for the next cycle, or for check-ups at a later stage, because of transportation costs. Some children only return when they are very sick, and often die soon thereafter.[247]

There are also too few ambulances and they are often not equipped to work in rural areas. Patients in need of transportation are frequently asked to pay for ambulance fuel costs, or to organize their own transportation.[248] A local government official in Kisumu described transportation costs within the province, or to one of the two Kenyan referral hospitals, as "a huge issue." For example, fuel for an ambulance to go from Nyanza's provincial capital to the nearest national referral hospital, in Eldoret, costs about 5000KSh (US$61).[249]

While transportation is mostly a problem in rural areas, it is also a barrier to health care and pain treatment for patients in Nairobi's slums. Community health workers in the Mathare slum described taking sick children to hospital on crowded buses, a trip that can take several hours. One community health worker told of a child who became ill during the night. His family could not afford a taxi to take him to the hospital, so decided to wait and take him on a bus, but he died before morning.[250]

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[245] Human Rights Watch interview with Rebecca A., age 20, and with her mother, Nyangoma, Bondo district, February 27, 2010.

[246] Human Rights Watch interview with Patrick O., age 10, Nyangoma, Bondo district, Nyanza province, February 27, 2010; Human Rights Watch interview with aunt of Sarah A., age three, Nyangoma, Bondo district, February 28, 2010. Patrick suffered from sickle cell disease, and Sarah from a birth defect.

[247] Human Rights Watch interview with Dr. Juliana Otieno, New Nyanza General Hospital, Kisumu, March 1, 2010; Human Rights Watch interview with oncology nurse, Kenyatta National Hospital, Nairobi, February 25, 2010.

[248] Ministry of Public Health and Sanitation, "Strategic Plan 2008-2012," p. 17; Human Rights Watch interview with medical officer in charge, District Medical Office, Kisumu East, Kisumu, March 2, 2010; Human Rights Watch interview with head nurse and a second nurse, Bondo District Hospital, March 1, 2010.

[249] Human Rights Watch interview with medical officer in charge, District Medical Office, Kisumu East, Kisumu, March 2, 2010.

[250] Human Rights Watch interview with community health worker B, Mathare slum, Nairobi, February 26, 2010; see also Human Rights Watch, *A Question of Life or Death,* p. 54.

IV. Kenya's Legal Obligations Regarding Palliative Care and Pain Treatment

International and Kenyan laws contain important guarantees for the child's rights to health and to protection from degrading conditions. These are binding on the government, yet Kenya violates many of these legal obligations in the context of children's access to pain treatment and palliative care.

The Child's Right to the Highest Attainable Standard of Health

The new Kenyan Constitution provides that every person has a right to the highest attainable standard of health, which includes health care services.[251] The Constitution requires the State to take legislative, policy and other measures, including the setting of standards, to achieve the progressive realization of the right to health.[252] In allocating resources, the State is required to "give priority to ensuring the widest possible enjoyment of the right ... having regard to prevailing circumstances, including the vulnerability of particular groups or individuals."[253] Children have a right to basic health care, which is not subject to progressive realization or limited by available resources.[254]

Kenya is a state party to the several human rights treaties that enshrine the child's right to the highest attainable standard of physical and mental health, including the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC), the African Charter on Human and Peoples' Rights, and the African Charter on the Rights and Welfare of the Child.[255] Under international law, the right to the highest attainable standard of health is subject to "progressive realization," requiring each state party to "to take steps ... to the maximum of its available resources" to achieve the full realization of the right.[256] The Committee on Economic, Social and Cultural Rights (CESCR), the body charged with interpreting and monitoring compliance with the ICESCR, has held that states have a "specific and continuing obligation to move as expeditiously and

[251] Constitution of Kenya, art. 29 (b).

[252] Ibid., art. 21(2).

[253] Ibid., art. 20(5)(b).

[254] Ibid., art. 53(1)(c).

[255] ICESCR, art. 12; CRC, art. 24; The 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, acceded to by Kenya January 23, 1992, http://www1.umn.edu/humanrts/instree/ratz1afchr.htm (accessed September 8, 2008), art. 16; and the African Charter on the Rights and Welfare of the Child, OAU Doc. CAB/LEG/24.9/49 (1990), November 29, 1999, ratified July 25, 2000, art. 14.

[256] ICESCR, art 2.

effectively as possible towards the full realization" of the right to health and must "refrain from interfering directly or indirectly with [its] enjoyment."[257]

The CESCR has called for an integrated approach to the provision of "preventive, curative and rehabilitative health treatment,"[258] which "should not disproportionately favour expensive curative health services which are often accessible only to a small, privileged fraction of the population."[259] The Committee has specifically called for "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."[260] States must refrain from actions that interfere with access to palliative care, and take reasonable steps to facilitate its development, and its integration into the health care system as a whole.

In addition, the CESCR has said that a state party to the ICESCR "cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations … which are non-derogable."[261] The core obligations defined by the committee that are relevant to palliative care include: providing essential medicines; ensuring nondiscriminatory access to health facilities, especially for vulnerable or marginalized groups; ensuring equitable distribution of all health facilities, goods and services; and adopting and implementing a national public health strategy and plan of action addressing the health concerns of the whole population with particular attention to all vulnerable and marginalized groups.[262] Relevant obligations of "comparable priority" include: ensuring child health care; taking measures to treat and control epidemic and endemic diseases; providing education and access to information for important health problems; and providing appropriate training for health personnel.[263] The CESCR has also stressed the "obligation of all States parties to take steps, individually and through international assistance and cooperation … towards the full realization of the rights recognized in the Covenant, such as the right to health."[264]

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[257] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, paras. 30 and 33.

[258] Ibid., para. 25.

[259] Ibid., para. 19.

[260] Ibid., para. 25. While the Committee included this reference in a paragraph on the right to health for older persons, the wording clearly indicates that it applies to all chronically and terminally ill persons.

[261] Ibid., para. 47.

[262] Ibid., para. 43.

[263] Ibid., para. 44.

[264] Ibid., para 38.

The right to health is also enshrined in the Children Act of Kenya, which aims to implement international law by "[giving] effect to the principles of the CRC and the African Charter on the Rights and Welfare of the Child."[265] The Children Act states that:

> Every child shall have a right to health and medical care the provision of which shall be the responsibility of the parents and the Government.[266]

The Act provides that if a child is in need of medical care that his or her caregiver is failing to furnish, a children's officer may take him or her to a registered health institution for treatment, and expenses will be defrayed out of public funds.[267]

The Child's Right to Protection from Discrimination

The new Kenyan Constitution provides that the State and no person shall discriminate against any person on any ground, including age or health status.[268] Under national and international law, children have the right to access health care without discrimination on the basis of age or health status, among other grounds. The Kenyan Children Act, the ICESCR, the CRC, the African Charter on Human and Peoples' Rights and the African Charter on the Rights and Welfare of the Child all protect children from discrimination on various grounds, including "other status."[269] Bodies responsible for interpreting international conventions have stated that "other status" includes both age and health status.[270] 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.

The Child's Right to Information and Participation in Health care

In addition to the treatment of pain and other symptoms, palliative care emphasizes the importance of good communication. This approach upholds the child's right to "seek,

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[265] The Children Act, No.8 of 2001, Laws of Kenya, introduction.

[266] The Children Act, sec. 9.

[267] Ibid., sec. 121.

[268] Constitution of Kenya, arts. 27(4) and (5).

[269] 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.

[270] 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.

receive and impart information of all kinds," found in both the CRC and the new Kenyan Constitution, and the principles, enshrined in the CRC, that a child's views should be given due weight in accordance with his or her age and maturity, and that children and parents should be informed and supported about child health.[271]

Interpreting these provisions of the CRC, the Committee on the Rights of the Child has said that "the child's right to express his or her views and to participate … applies to individual health-care decisions," and that:

> Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capabilities. They should be provided with information about proposed treatments and their effects and outcomes.[272]

The Committee on the Rights of the Child has also emphasized that adolescents have the right to participate "actively in planning and programming for their own health and development."[273] If they are of sufficient maturity, informed consent shall be obtained from the adolescent, and parental consent shall not be necessary.[274]

The Child's Right to be free from Cruel, Inhuman or Degrading Treatment

In some circumstances, the denial of pain treatment may violate the prohibition of cruel inhuman or degrading treatment in international law.

The right to be free from cruel, inhuman or degrading treatment is recognized in the new Kenyan Constitution, the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, the African Charter of Human and Peoples' Rights, and other international instruments.[275] Apart from prohibiting the use of torture and other cruel,

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[271] CRC, arts. 12, 13 and 24(2)(e); Constitution of Kenya, art.33(1)(a).

[272] UN Committee on the Rights of the Child, "The right of the Child to be heard," General Comment No. 12, U.N. Doc. CRC/C/GC/12 (2009) paras. 98 and 100.

[273] UN Committee on the Rights of the Child, "Adolescent health in the context of the Convention on the Rights of the Child," General Comment No. 4, U.N. Doc. CRC/GC/2003/4 (2003), paras. 39(b) and 39(d).

[274] Ibid., para. 32.

[275] Constitution of Kenya, art. 29(f); African [Banjul] Charter on Human and Peoples' Rights, art. 5; 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, art. 16; ICCPR, art. 7; Universal Declaration of Human Rights (UDHR), adopted December 10, 1948, G.A. Res. 217A(III), U.N. Doc. A/810 at 71 (1948), art. 5.

inhuman, or degrading treatment or punishment, the right also creates a positive obligation for states to protect persons in their jurisdiction from such treatment.[276]

As part of this positive obligation, states must take steps to protect people from unnecessary pain related to a health condition, according to a joint letter by UN Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment Manfred Nowak, and UN Special Rapporteur on the Right to Health Anand Grover:

> 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.[277]

In a report to the Human Rights Council, Nowak later specified that "the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment" and that "all measures should be taken to … overcome current regulatory, educational and attitudinal obstacles to ensure full access to palliative care."[278]

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 of torture and cruel, inhuman, or degrading treatment;
- The state is, or should be, aware of the level and extent of the suffering;

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[276] Convention Against Torture, art. 16; UN Human Rights Committee, "Article 7 (Prohibition of torture, or other cruel treatment or punishment (Art. 7)," General Comment No. 20, Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N.Doc. HRI/GEN/1/Rev.9 (Vol. I), http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G08/422/35/PDF/G0842235.pdf?OpenElement (accessed April 27, 2010) p. 200, para. 8; See also the judgment of the European Court of Human Rights in Z v United Kingdom (2001) 34 EHHR 97.

[277] Joint letter by the UN special rapporteur on the prevention of torture and cruel, inhuman or degrading treatment or punishment, Manfred Nowak, and the UN special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, to the Commission on Narcotic Drugs, December 2008. A copy of the letter is available at http://www.ihra.net/Assets/1384/1/SpecialRapporteursLettertoCND012009.pdf (accessed April 27, 2010).

[278] Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, U.N. Doc. A/HRC/10/44, January 14, 2009, paras. 72 and 74(e).

- Treatment is available to remove or lessen the suffering but no appropriate treatment is 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.

The Child's Right to Protection from Abuse and Neglect

The new Kenyan Constitution provides that every child has the right to be protected from abuse, neglect, and inhuman treatment.[279] Similar protections are found under the Children Act.[280]

Under the CRC, parents, guardians, and other persons caring for a child, have the "primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development."[281] The convention protects children from "all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child."[282] The African Charter on the Rights and Welfare of the Child has similar protections.[283]

While the convention emphasizes the responsibility of caregivers, it also makes clear that the state has a role in child protection. Children who are deprived of their family environment, or who cannot, in their own best interest, be allowed to remain in that environment, are entitled to special protection and assistance provided by the state. The state must ensure alternative care for the child, which can include foster placement, adoption or placement in suitable institutions for the care of children.[284]

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[279] Constitution of Kenya, art. 53(1)(e).

[280] The Children Act, secs.13 and 15.

[281] CRC, art.27.

[282] CRC, art.19.

[283] African Charter on the Rights and Welfare of the Child, arts.16 and25.

[284] CRC, art.20. This provision reinforces article 24(1) of the ICCPR, which guarantees every child "the right to such measures of protection as are required by his status as a minor."

V. The Crucial Role of Kenyan Civil Society

Civil society groups are spearheading efforts to increase access to palliative care in Kenya. One of the main organizations working on the issue is the Kenya Hospices and Palliative Care Association (KEHPCA). Funded mostly by international donors, KEHPCA was registered as an NGO in 2005 and officially launched in 2007. Although a relatively new organization, KEHPCA has undertaken a very broad range of activities, including raising awareness through community events and media; offering sensitization workshops for health care professionals; assessing needs and evaluating services; and developing curriculum. Among other activities, KEHPCA organized Kenya's first palliative care conference in 2008, and has worked with other organizations to ensure that palliative care is addressed in the National Cancer Control and Prevention Bill currently under consideration by the Kenyan parliament. KEHPCA has also provided short courses in palliative care for hundreds of health professionals and volunteers.[285]

Other organizations working to increase access to pain treatment and palliative care include the Kenya Society for Pain, the Kenya Cancer Association, and the Kenya Treatment Access Movement.[286] None of these organizations specializes in palliative care needs of children, although one Nairobi-based organization, Hope for Cancer Kids, specializes in the needs of children with cancer, including palliative care.

There are also many Kenyan NGOs working to protect the rights of children living with HIV, including their access to medical care, psychosocial support, and legal protection. While support from child rights groups and children's charities sometimes includes aspects of palliative care—such as home-based care and psychosocial counseling—they usually do not provide treatment for severe pain.

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[285] KEHPCA, Annual Report 2008; Human Rights Watch interview with Dr. Zipporah Ali, Kenyan Hospice and Palliative Care Association, March 3, 2010. Among the organization's donors are Open Society Institute, The Diana Princess of Wales Memorial Fund, African Palliative Care Association (APCA), Hospice Care Kenya, the True Colours Trust and Catholic Relief Services. The United Kingdom Department for International Development provides funding through APCA, and in the past funding has been provided the United States Centers for Disease Control and Prevention (CDC).

[286] Organizations such as the International Union Against Cancer and the WHO Access to Controlled Medications Programme work at the international level to improve access to opioids in all countries.

VI. International Donors' Lack of Attention to Palliative Care

International donors are uniquely placed to facilitate the integration of palliative care into Kenya's HIV/AIDS response. To date, however, they have failed to do so effectively.

Kenya's most important international health donor is the United States, through the President's Emergency Plan for AIDS Relief (PEPFAR). In 2009, PEPFAR funding for Kenya was approximately US$534 million, more than the Kenyan government's total health budget.[287] The legislation that established PEPFAR in 2003 included a non-binding direction that 15 percent of PEPFAR funds should be spent on palliative care. Although this direction was omitted from the legislation that funded PEPFAR from 2008, PEPFAR has assigned very large sums to activities that it considers palliative care.[288] However, PEPFAR has adopted a very broad definition of palliative care, including routine HIV counseling and testing; prevention and treatment of opportunistic infections; and HIV prevention and behavior-change counseling. This definition is much broader than the WHO definition of palliative care, and as a result, little real progress has been made towards improving access to pain treatment.[289]

In 2007, 600 facilities in Kenya received PEPFAR funding to provide palliative care. A survey covering 10 percent of those facilities found that commonly provided services included pre- and post-test counseling (90 percent), prevention programs (90 percent), nutrition programs (98 percent) and patient support groups (75 percent). By contrast, none of the facilities stocked oral morphine or any other strong oral opioid for treating chronic severe pain. While 83 percent of the facilities reported dispensing weak non-opioid pain relievers, such as paracetamol, only 27 percent reported dispensing weak opioids, such as codeine.[290]

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[287] Human Rights Watch email correspondence with Elizabeth Brennan, US State Department, July 15, 2010; government budget in GTZ Health Sector Programme Kenya, "Estimated Government Spending 2009/2010. Kenyan Health Sector Budget Analysis," 2010 (on file at Human Rights Watch).

[288] United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003, sec. 402(b)(2). The Act states that it is the "sense of the Congress" that effective distribution of PEPFAR funds includes spending 15 percent on palliative care for people with HIV/AIDS. This is an authoritative recommendation but does not bind the agencies implementing PEPFAR. The Act was amended to remove the reference to palliative care by the Tom Lantos and Henry J. Hyde United States Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008, sec. 402.

[289] The United States President's Emergency Plan for AIDS Relief, "HIV/AIDS Palliative Care Guidance #1," February 3, 2006, http://www.pepfar.gov/guidance/75827.htm (accessed March 28, 2010).

[290] Three facilities (5 percent) reported having stronger opioids, but an inspection of pharmacy data revealed that only one of the facilities actually had a strong opioid in stock, and this was in an injectable form. Harding et. al, "The Nature and Scope of PEPFAR Palliative Services in Kenya: A Cross-sectional Survey" in *Scaling Up Through Partnerships: Overcoming Obstacles to Implementation*, abstract book of the 2008 HIV/AIDS Implementers Meeting, http://www.hivimplementers.com/2008/pdf/OGAC_08_BookHR.pdf (accessed April 27, 2010), pp. 257-8.

Professionals working for PEPFAR-funded programs confirmed that this situation remained unchanged in 2010. PEPFAR-funded facilities usually stock weak non-opioid pain relievers but no strong opioids, and there is no systematic effort to ensure the availability of oral morphine or alternative medicines for treating severe chronic pain.[291]

PEPFAR funds the Supply Chain Management System (SCMS), which the Kenyan and United States governments could use to improve the availability of oral morphine and other pain medicines. SCMS is a collaboration of private-sector, faith-based and nongovernmental organizations that "helps strengthen and build reliable, secure and sustainable supply chain systems [and] helps to reduce the price of essential medicines by working closely with clients to plan future procurement, pooling orders to buy in bulk [and] establishing long-term contracts with manufacturers."[292] Although governments and PEPFAR-funded health facilities can purchase oral morphine from SCMS, very few have done so.[293] This may be a missed opportunity.

PEPFAR staff members include clinicians who are influential in the countries where they work and in international institutions such as WHO. For this reason, increased attention to pain treatment within PEPFAR could help bring about important reforms in Kenya and internationally, such as the inclusion of pain treatment and palliative care in HIV clinical guidelines; the revision of medical and nursing school curricula to include pain treatment and palliative care; the inclusion of pain assessment in initial patient assessment forms, and the addition of access to pain treatment as a factor in the routine monitoring and evaluation of HIV programs.

Other key international health donors in Kenya include the Global Fund to Fight AIDS, Tuberculosis and Malaria; the governments of the United Kingdom, Japan, and Germany; and multilateral agencies such as UNICEF, UNAIDS, the World Bank, and the European Union.[294]

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[291] Human Rights Watch interview with staff of the CDC, Kisumu, March 2, 2010; Human Rights Watch interview with a doctor in charge of a health facility receiving PEPFAR funding for palliative care, April 19, 2010. At the international level, PEPFAR's implementing agencies have begun work to assist governments to assess and reform drug control regulations that impede the availability of opioids.

[292] SCMS, "About Us," http://scms.pfscm.org/scms/about (accessed March 28, 2010).

[293] Human Rights Watch email correspondence with a staff member of the CDC, March 16, 2010.

[294] USAID, "Kenya," http://www.usaid.gov/pubs/cbj2003/afr/ke/ (accessed March 28, 2010); The Global Fund to Fight AIDS, Tuberculosis and Malaria has made grants totally more than $329 million for Kenya, including more than $200 million for HIV/AIDS programs. The Global Fund, "Kenya and the Global Fund," http://www.theglobalfund.org/programs/country/?countryID=KEN&lang=en (accessed March 28, 2010). The Global Fund resumed making grants to the Kenyan Government in 2007 after refusing its applications for a period because Kenya had failed to submit audited accounts for past grants or delayed grant reports: Wairagala Wakabi, "Kenya's mixed HIV/AIDS response," *The Lancet*, vol. 369, issue 9555 (January 6, 2007), pp. 17-18.

There are also two important private US donors, the Clinton Health Access Initiative—which has a focus on pediatric HIV treatment—and the Bill and Melinda Gates Foundation.[295]

Unfortunately, international funding for HIV/AIDS programs dwarfs funding for strengthening the health system as a whole, as well as for child health care, cancer treatment, and palliative care. Nonetheless, international donors have also made some important contributions to these areas. The US government has helped to fund a new children's ward at Kisumu's provincial hospital and is supporting some research and treatment on childhood cancer. Some international NGOs support Kenyan hospices, including Hospice Care Kenya, the Diana Princess of Wales Memorial Fund Palliative Care Initiative, and Hospice Care Inc.

Many international donors and NGOs serve orphans and vulnerable children (OVCs), and specifically children affected by HIV. However, their programs usually do not explicitly include palliative care.

[295] Clinton Foundation, "Clinton HIV/AIDS Initiative: Our Approach," http://www.clintonfoundation.org/what-we-do/clinton-hiv-aids-initiative/our-approach (accessed March 28, 2010); Bill and Melinda Gates Foundation, "Global Health Program," http://www.gatesfoundation.org/global-health/Pages/overview.aspx (accessed March 28, 2010).

VII. Providing Pain Treatment and Palliative Care with Limited Resources

The Example of Uganda

Significant improvements in access to palliative care in Uganda, a country with considerably fewer resources than Kenya,[296] demonstrate the potential for government leadership to rapidly scale up access to palliative care. In developing strategies to improve pain treatment and palliative care, Kenya could look closely at Uganda's experience.

In recent years, Uganda has significantly boosted its capacity for palliative care. There are now at least 50 facilities providing palliative care services, including morphine.[297] In order to reach more patients in need, community services for home-based palliative care have been greatly strengthened. Many patients can now receive palliative care in their own homes.

The Ugandan government has worked closely with palliative care organizations to expand access. In 1998, representatives of the Ugandan government, nongovernmental organizations, and WHO met at a conference entitled "Freedom from Cancer and AIDS Pain" to discuss ways to make pain treatment widely available.[298] A task force, including representatives of the Ministry of Health and WHO, was formed to draft a national policy on palliative care, which the Ministry of Health incorporated into its Health Service Strategic Plan (HHSP) for 2000-2005, and the current HHSP II for 2006-2011. The current strategic plan states that all hospitals and health centers should provide palliative care, that necessary medicines should be available, and that palliative care should be integrated into the curriculum of health training institutions. It also emphasizes the need to strengthen referral systems and community-based palliative care.[299]

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[296] Kenya and Uganda are similar in population size (Kenya: 37.5 million; Uganda: 30.1 million, as of 2007), but Kenya has a significantly larger gross national income per capita (Kenya: $1,540; Uganda: $920, purchasing power parity at international dollar rate (PPP), 2007) and fewer people living on less than $1 (PPP) per day (Kenya: 19.7 percent; Uganda: 51.5 percent, 2005). Kenya has approximately twice as many doctors and nurses as Uganda (Kenya: 4,506 doctors, 37,113 nurses; Uganda: 2,209 doctors, 18,960 nurses, 2000-2007) and more hospital beds (hospital beds per 10,000 people: Kenya: 14; Uganda: 10, 2000-2008). All statistics from WHOSIS.

[297] Palliative Care Association of Uganda (PCAU), "Audit Report of Palliative Care Services in Uganda," April 2009, http://www.theworkcontinues.com/document.asp?id=1386&pageno= (accessed March 27, 2010), pp. 7 and 12.

[298] 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).

[299] Jack Jagwe and Anne Merriman, "Uganda: Delivering Analgesia in Rural Africa: Opioid Availability and Nurse Prescribing," *Journal of Pain and Symptom Management*, vol. 33, no. 5 (May 2007); Stjernsward, "Uganda: Initiating a Government Public Health Approach to Pain Relief and Palliative Care," *Journal of Pain and Symptom Management*.

To implement the policy, a national palliative care team was established.[300] In 2004, the law was amended to allow nurses and clinical officers to prescribe morphine, once they have completed a nine-month palliative care course.[301] More than 80 nurses and clinical officers have graduated from Hospice Africa Uganda's Clinical Palliative Care Course. The Ministry of Health started importing oral morphine powder and providing oral morphine solution to public health facilities at no cost. It has also published clinical guidelines on palliative care.

Hospice Africa Uganda established a specialist children's palliative care service in 2006. The service provides home-based and outpatient palliative care in Kampala and visits patients at the national children's oncology ward, also in Kampala. The service is led by nurses who can call upon doctors as required. Elements of the children's palliative care service include pain and symptom management, basic needs support (providing food, clothing, blankets and transportation costs), chemotherapy, patient information services, a volunteer-led play and learning program, and child advocacy and protection. A review of the specialist children's service found that it significantly increased the number of children referred to palliative care and the proportion of palliative care patients who were children. Adherence to chemotherapy also improved. The average cost per child was $75 per year.[302]

Hospice Africa Uganda's children's palliative care service demonstrates the benefits of specialized palliative care services for children, but it can only serve a tiny fraction of children in need of palliative care in Uganda—it is inaccessible to children who live outside the capital, most of whom do not have the means to travel there.

In 2004, the law was amended to allow nurses and clinical officers to prescribe morphine, once they have completed a nine-month palliative care course.[303] More than 80 nurses and clinical officers have graduated from Hospice Africa Uganda's Clinical Palliative Care Course. The INCB has commended Uganda's efforts to improve access to pain treatment, including by reform of its narcotics control laws so that specially trained nurses can prescribe morphine.[304]

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[300] It is chaired by the Ministry of Health's Commissioner for Clinical Services, with other members representing the Ministry of Health, WHO, the national AIDS control program, Makerere University, palliative care providers, the Palliative Care Association of Uganda and the African Palliative Care Association.

[301] Jagwe and Merriman, "Uganda: Delivering Analgesia in Rural Africa," *Journal of Pain and Symptom Management*.

[302] Amery et al., "The Beginnings of Children's Palliative Care," pp.1015-1021. The number of children referred to palliative care increased from 120 to 275 (129%) and the proportion of patients who were children increased from 19% to 35%.

[303] Jagwe and Merriman, "Uganda: Delivering Analgesia in Rural Africa," *Journal of Pain and Symptom Management*.

[304] INCB, *Report of the International Narcotics Control Board for 2004* (New York: United Nations, 2005), pp. 32-33.

When Human Rights Watch asked Kenyan health workers about the possibility of allowing nurse prescribing of opioids, some expressed reservations. Some doctors felt that nurses are not qualified to prescribe strong medicines such as morphine,[305] and some nurses were concerned that doctors would abdicate responsibility for palliative care entirely if nurses do the prescribing.[306] But Kenya, like Uganda, faces a great shortage of doctors, and the existing doctors are concentrated in a few large health facilities.[307] The Ugandan experience demonstrates that when nurse prescribing is part of a broader change, in which palliative care is more fully integrated into the health system, it can be a useful part of a larger strategy.[308]

Despite progress, many challenges remain in ensuring access to palliative care throughout Uganda. Some of the nurses trained in palliative care are not using their training because morphine is not available where they work or because hospital administrators are not supporting their efforts—for example, by failing to assign them to care for patients with life-limiting disease. District health departments do not have defined palliative care budgets and inadequate distribution systems for morphine remain a problem.[309] Nonetheless, Uganda's progress in scaling up access to palliative care demonstrates what can be quickly achieved with limited resources and political will.

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[305] Human Rights Watch interview with Prof. Nduati, Nairobi, February 24, 2010; Human Rights Watch interview with Dr. Esther Munyoro, head of the palliative care unit, Kenyatta National Hospital, Nairobi, February 24, 2010.

[306] Human Rights Watch interview with palliative care nurse A, Kenyatta National Hospital, Nairobi, February 24, 2010; Human Rights Watch interview with head nurse and a second nurse, Bondo District Hospital, March 1, 2010.

[307] Kenya has approximately one doctor for every 10,000 people. WHOSIS.

[308] David Makumi, "Cancer Pain Management in Kenya in the Context of World Health Organization Guidelines," presentation at UICC World Cancer Congress 2006, July 8-12, 2006, http://2006.confex.com/uicc/uicc/techprogram/P9415.HTM (accessed March 31, 2010).

[309] PCAU, "Audit Report of Palliative Care Services in Uganda," p. 8.

Detailed Recommendations

To The Government of Kenya

To the Ministry of Public Health and Sanitation, and the Ministry of Medical Services

Availability of medicines and treatment

- Urgently improve availability of drugs for moderate to severe pain, in particular by:
  - Ensuring that strong opioids, including morphine tablets and morphine powder for oral solution, are available at all national, provincial, and district hospitals, in accordance with Kenya's international legal obligation to provide essential medicines, and with the Kenya Essential Drugs List.
  - Ensuring that oral morphine is procured centrally by the Kenya Medical Supplies Agency (KEMSA).
  - Ensuring that medicines for neuropathic pain are available in all district, provincial, and national hospitals, including in formulations suitable for children.
  - Investigate whether procuring and distributing morphine and other pain medicines using Supply Chain Management System or a nongovernment organization could decrease their cost and ensure better supply across the country.
- Work with the Ministry of Finance to remove the tax on morphine powder.
- Create palliative care units with expertise in children's palliative care in district, provincial, and national hospitals, ensure that existing services respond to the needs of children and their families, and raise awareness about the existence of these services.
- Implement a program of support to home-based palliative care with expertise in children's palliative care through existing hospices and palliative care units or newly established services.
- Strengthen the role of community health workers and community health extension workers in providing home-based palliative care. Community health workers should be equipped with basic care kits, receive modest compensation, and have strong links with health care professionals. In rural areas they should be provided with transportation.
- Provide psychological support to children with life-limiting diseases and their caregivers, through the employment of child psychologists, counselors, or social workers in hospital settings and in home-based care.

- When reviewing the Kenya Essential Drugs List, consider revising the opioid analgesics included on the list to conform to the World Health Organization (WHO) Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children.

Policy

- Develop a policy and plan of action on palliative care, with a specific focus on the needs of children. Such a policy and plan of action should be developed in consultation with other relevant government ministries and agencies, nongovernmental organizations, and international agencies. As a first step, organize a stakeholders meeting to map existing barriers and discuss strategies for overcoming them.
- Assign officers of the Ministry of Medical Services and the Ministry of Public Health and Sanitation responsibility for implementing the policy, and allocate them a budget.
- Develop a medical protocol on pain management for children, in coordination with WHO, which is currently developing new guidelines on chronic pain in children.
- Develop legislation on the medical use of opioids, as envisaged by the Kenya National Drug Policy. Such legislation should recognize that opioids like morphine are indispensable for the relief of pain, promote the availability of opioids for medical purposes, and protect health care professionals from unnecessarily harsh sanctions for inadvertent breach of drug control regulations. In the short term, until legislation is enacted, develop guidelines on the appropriate use of controlled medicines, including morphine, and the legal requirements for prescribing and dispensing them. Ensure the guidelines and any new legislation is well publicized and disseminated to all physicians.
- Ensure that the National Cancer Control and Prevention Bill and Strategy contain strong provisions addressing pain treatment and palliative care, including for children.
- Encourage hospitals to institutionalize pain management, for example by regularly assessing whether patients are receiving adequate pain management and including pain on nurses' initial patient assessment forms.
- Make pain treatment and palliative care an integral part of the HIV/AIDS response, and include this explicitly into the next Kenya National HIV/AIDS Strategic Plan. This should include better availability of pain medicines and palliative care at facilities providing HIV services on site or in the home.

- Support the efforts of civil society groups, such as the Kenya Hospices and Palliative Care Association, to improve palliative care.

Awareness and education

- Raise public awareness around the right to pain relief, and on the availability of treatment for severe pain in Kenya. Include this as an aspect of information campaigns on HIV and cancer.
- Improve training for health workers on pain management and palliative care, including for children:
  - by improving the curriculum for medical and nursing students, in partnership with Kenyan universities;
  - by increasing continuing professional development opportunities for doctors;
  - by increasing opportunities for health care workers to get vocational training; and
  - by providing training on pediatric pain management and pediatric palliative care for pediatricians, pediatric nurses, and other health workers treating children.
- Provide training to community health workers on pain treatment and palliative care for adults and children with life-limiting disease, including cancer.
- Ensure that health workers are trained in how to communicate with child patients and their families, especially in how to disclose information about illness, taking into consideration the child's age, maturity, and family dynamics, and the clinical context.
- Raise awareness among health workers about the current Narcotic Drugs and Psychotropic Substances Control Act, which allows for the use of opioids for medicinal purposes, and any new legislation or guidelines on this issue.

Economic access barriers and health system strengthening

- Take steps to improve access to health care for children, through the establishment of a National Social Health Insurance Fund that ensures health care provision for all children; and through the full implementation of the government's policy of free health care at the local level for all children under the age of five.
- Take steps to strengthen the referral system, for example by providing transport between health care facilities without requiring patients to pay for fuel.
- Strengthen the role of community health workers by providing them with basic health care supplies and transportation where needed, and introducing compensation for their services.

- Take steps to lower the price of chemotherapy for children, for example by subsidizing its cost.
- Help set up schemes to provide children on anti-retroviral treatment (ART) with key nutrients, in order to improve adherence to treatment.
- Use information campaigns to raise awareness that the practice of detaining children in hospitals is illegal and instruct hospitals to immediately release all children detained due to unpaid bills. Investigate and prosecute cases of unlawful detention in hospitals and establish a compensation scheme for children unlawfully detained.

Child neglect

- In cooperation with the Ministry for Gender and Children Affairs, create and intensify linkages and referral mechanisms between the health system and the child protection system, in order to improve monitoring and intervention for children in need of protection.
- In cooperation with the Ministry for Gender and Children Affairs, provide training on child protection to health care workers, including community health workers and others providing home-based care; and provide training to children officers about the child's right to health, including palliative care, and about how to access health care services for children.

To the Ministry of Finance

- Remove the tax on morphine powder.

To the National Aids Control Council

- Make pain treatment and palliative care an integral part of the HIV/AIDS response, and include this explicitly into the next Kenya National HIV/AIDS Strategy. This should include better availability of pain medicines and palliative care at facilities providing HIV services on site or in the home.

To the Kenya Medical Supplies Agency (KEMSA)

- Procure oral morphine and distribute it to all district, provincial, and national hospitals, in accordance with the Kenya National Drug Policy and Kenya Essential Drugs List.

To the Ministry of Gender and Children Affairs

- In cooperation with the Ministry of Public Health and Sanitation and the Ministry of Medical Services, create and intensify linkages and referral mechanisms between the health system and the child protection system.
- In cooperation with the Ministry of Public Health and Sanitation, provide training on child protection to community health workers and others providing home-based care; and provide training to children officers on the child's right to health and existing health services.
- In cooperation with the Ministry of Public Health and Sanitation and the Ministry of Medical Services, track cases of child neglect, and intervene when necessary.

To the Kenyan National Assembly

- Enact the National Cancer Control and Prevention Bill, ensuring that it retains strong provisions addressing pain treatment and palliative care, including for children.
- Enact the National Social Health Insurance Bill, ensuring that the planned National Health Insurance Fund provides health care for all children.
- Enact legislation on the medical use of opioids, as envisaged by the Kenya National Drug Policy. Such legislation should recognize that opioids like morphine are indispensable for the relief of pain, promote the availability of opioids for medical purposes, and protect health care professionals from unnecessarily harsh sanctions for inadvertent breach of drug control regulations.

To the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), the US President's Emergency Plan for AIDS Relief (PEPFAR), and Other Health Donors

- Ensure that all patients using donor-funded clinical services for life-limiting illness can access palliative care, either by providing it as part of the service, or by strengthening hospice and public palliative care services and facilitating access to them.
- Provide technical and financial assistance to the Kenyan government in its efforts to boost pain treatment and palliative care for children, as outlined above.
- Support efforts to improve access to health care for children, through improved health financing systems and strengthening the health system as a whole. In particular, support steps to lower the price of chemotherapy for children.

- Ensure that donor-funded clinical programs on HIV provide palliative care and adequate pain treatment, including with opioids and other drugs for neuropathic pain.
- Scale up funding for cancer treatment, including efforts to make chemotherapy cheaper, especially for children.

To the World Health Organization (WHO)

- Complete treatment guidelines on chronic pain in children, and make them widely available to government, health workers, and NGOs in Kenya and other countries with poor pain management.
- Through the Access to Controlled Medications Programme, engage the Kenyan government to improve access to opioid pain medicines.
- Through the "Make Medicines Child Size" campaign, work with pharmaceutical companies to ensure that medicines for neuropathic pain are available in formulations suitable for children.

To International and Kenyan NGOs, and Private and Church Health Services

- Develop policies on pain treatment and palliative care.
- Ensure that all patients using clinical services for life-limiting illness can access palliative care, either by providing it as part of the service, or by strengthening hospice and public palliative care services and facilitating access to them.
- Establish palliative care services for children, ensuring that strong opioids and medicines for neuropathic pain are available.
- Train health workers on palliative care and pain treatment, including for children.
- Strengthen the role of community health workers and community health extension workers in providing home-based palliative care. Community health workers should be equipped with basic care kits, receive modest compensation, and have strong links with health care professionals. In rural areas they should be provided with transportation.

Acknowledgments

This report was researched and written by Juliane Kippenberg, senior researcher in the Children's Rights Division of Human Rights Watch, and Laura Thomas, fellow in the Health and Human Rights Division of Human Rights Watch.

The report was reviewed by Diederik Lohman, senior researcher in the Health and Human Rights Division; Joseph Amon, director of the Health and Human Rights Division; Ben Rawlence, researcher in the Africa Division; Agnes Odhiambo, researcher in the Women's Rights Division; and Clive Baldwin, senior legal advisor. It was edited by Zama Coursen Neff, deputy director of the Children's Rights Division and Robin Shulman, consultant to the program office.

Production assistance was provided by Kyle Knight and Cassandra Mikicic, associates in the Children's Rights division; Anna Lopriore, creative manager; Grace Choi, publications director; and Fitzroy Hepkins, mail manager.

We would like to thank Dr. Zipporah Ali and her colleagues from the Kenya Hospices and Palliative Care Association (KEHPCA) for sharing their analysis with us, providing us with assistance during our field research, and commenting on the draft report. All errors are our own. We would also like to thank Charles Olango for invaluable support during our research in Bondo district, Nyanza province.

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Needless Pain

Government Failure to Provide Palliative Care for Children in Kenya

In Kenya, hundreds of thousands of children suffer from HIV/AIDS, cancer, and other life-limiting illnesses, and they often experience severe, debilitating pain. Morphine and other medicines can cheaply and easily alleviate this pain, but very few sick children receive them. The World Health Organization considers oral morphine an essential medicine, as does Kenya's own drug policy. Yet the Kenyan government does not purchase it for public health facilities, as with other medicines, and it is available in just seven of the country's approximately 250 public hospitals.

Palliative care seeks to ease the suffering caused by life-limiting illness, by treating pain and other symptoms, and providing psychosocial support for children and their families. It aims not to cure, but to care for, those who are ill, but it can sometimes help curative treatment to succeed, for example, by enabling a sick child to eat, exercise, communicate, or adhere to a medication regimen. The Kenyan government has no policy on palliative care and has done little to ensure its availability, especially for children. This failure condemns children facing serious illness to unnecessary suffering.

Needless Pain, based on interviews with sick children, their family members, healthcare providers, government officials, and experts on pediatric medicine and palliative care, documents Kenya's failure to alleviate the pain and suffering of vulnerable children. It calls on the Kenyan government to increase the availability of oral morphine, to integrate palliative care into the public health system, to develop home-based palliative care services, and to educate healthcare workers about pain treatment and palliative care, including for children. International organizations and donors should support the Kenyan government to achieve this, particularly by integrating pain treatment and palliative care into their responses to HIV/AIDS.

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Community health worker Mary Njoki examines a child as the child's mother feels for a fever during a home-based care visit March 6, 2010 in Mathare, a slum in Nairobi.