

## Overview and Recommendations



Palliative care nurses and volunteers check up on a 67-year-old woman, who is paralyzed and taking morphine for pain in south Kerala.



# UNBEARABLE PAIN

Photographs by Brent Foster

Dr M.R. Rajagopal, a palliative care physician, consults a breast cancer patient (in blue sari) in Kerala.

**In late 2007 Muzaffar Iqbal, a 65-year-old rickshaw driver from a small village in Andhra Pradesh, first noticed a growth near his right armpit. When the growth became painful, he went to a local doctor who gave him a basic painkiller and suggested that he undergo a biopsy. Iqbal learned that he had lung cancer.**

As Iqbal sought and later underwent treatment, he developed a piercing chest pain that became excruciating. Though he repeatedly informed his doctors, he found them unresponsive. In an interview with Human Rights Watch, he said, “They sent me here, there, everywhere but nobody ever asked me if I had pain.” As the pain got worse and no



treatment was forthcoming from his healthcare providers, Iqbal unsuccessfully tried to self-medicate with paracetamol from a local pharmacy. Ultimately, his pain got so bad that he wished that “God would take me away...”<sup>1</sup>

Raj Ramachandran, a rubber-tapper from a small village in Kerala, had a similar experience. Ramachandran developed



a swelling in his neck in 2006, which turned out to be cancer of the parotid gland. After initial surgery seemed successful, Ramachandran had a recurrence in March 2007. Shortly after, he developed severe pain. Ramachandran's doctors would give him some medications when he discussed his pain with them but, he said, the paracetamol his wife bought at the

local pharmacy brought more relief than the medications he received from his doctors. His pain became so severe that he could no longer sleep, could not lie down, and wanted to end his life.<sup>2</sup>

Stories of suffering like those of Muzaffar Iqbal and Raj Ramachandran are all too common in India. Although





A paralyzed cancer patient outside the palliative care unit at MNJ Institute of Oncology, Hyderabad.



Palliative care nurses and volunteers walk to see a patient in the rural areas of south Kerala.



enormous problems exist with availability and accessibility of health services at all levels of care in India—due to limited resources and weak public healthcare services—the suffering of patients like Iqbal and Ramachandran can be easily and cheaply prevented. Morphine, the key medication for treating moderate to severe pain, is inexpensive, highly effective, and generally not complicated to administer.

Palliative care—a field of medicine that does not seek to cure but to improve the quality of life of patients with life-limiting illnesses<sup>3</sup>—can be delivered at limited cost both in the community through home-based care and at healthcare centers. It includes treatment of pain and of other problems, whether physical, psychosocial, or spiritual. Indeed, after considerable suffering, both Iqbal and Ramachandran ended up being cared for by palliative care programs—one offered by a cancer hospital in Andhra Pradesh, the other by a nongovernmental organization (NGO) in Kerala—where they received proper treatment for their pain, as well as psychological and spiritual support.

In this respect, Iqbal and Ramachandran are the exceptions. Leading palliative care experts in India estimate that more than one million people in India suffer from moderate to severe pain every year due to advanced cancer. That number rises considerably once people with non-advanced cancer, HIV and AIDS, and a variety of other progressive, incurable or otherwise life-limiting health conditions are included. These experts believe that more than seven million people may suffer from pain and other symptoms due to such illnesses and conditions annually. Only a small fraction of these people have access to adequate palliative health services. In 2008 India used an amount of morphine that was sufficient to adequately treat during that year only about 40,000 patients suffering from moderate to severe pain due to advanced cancer, about 4 percent of those requiring it.

Most patients with advanced cancer are simply sent home when curative treatment options—or money to pay for such treatment—are exhausted. Abandoned by the healthcare system at arguably the most vulnerable time of their lives, they face pain, fear, and anguish without professional support, and die in the confines of their homes. Even most large cancer hospitals in India, including 18 of 29 government-designated lead cancer centers, do not have personnel trained in palliative care or morphine and other strong pain medications. This is particularly startling given that about 70 percent of the patients seen at these hospitals are at such an advanced stage of cancer upon arrival that they are beyond cure; palliative care and pain management is the only benefit they may still receive.

Similarly, people with HIV and AIDS, paraplegics, patients with advanced renal disease, or elderly people who suffer from physical or psychological pain and require



A nurse prepares to administer an IV for a 72-year-old palliative care patient in Kerala.

palliative care services are unable to access them in most parts of India. Like most cancer hospitals, the vast majority of community care centers for people living with HIV, antiretroviral clinics, or secondary and primary health centers do not offer palliative care as they do not have the necessary medications, including morphine, or trained healthcare workers.

The World Health Organization (WHO) has recognized palliative care as an integral and essential part of comprehensive care for cancer, HIV, and other health conditions. With respect to cancer, for example, it has noted that, despite improvements in survival rates, *the majority of cancer patients will need palliative care sooner or later. In developing countries, the proportion requiring palliative care is at least 80 percent. Worldwide, most cancers*

*are diagnosed when already advanced and incurable ... [For these patients] the only realistic treatment option is pain relief and palliative care.*<sup>4</sup>

The WHO has urged countries to take action in three areas—policy making, education, and drug availability—that it sees as fundamental for the development of palliative care and pain management services. It has observed that these measures cost little but can have significant effect. In India major challenges exist in all three areas.

Government authorities in India, both at the central and state level, have done too little to make sure that palliative care and pain management services are available, or to facilitate their provision by the private sector or nongovernmental organizations. In fact, many state governments continue to enact complex narcotics regulations that actively impede the availability of morphine, despite a key recommendation by the central government to simplify them.



A palliative care physician assesses a patient's pain.

**POLICY.** The World Health Organization has recommended that countries establish a national palliative care policy or program. In India, however, a national policy or program does not exist, even though they exist for various other illnesses and conditions. The government has invested considerable resources in strengthening its cancer care system, but almost none of these funds have been allocated to palliative care provision, despite the fact that the majority of cancer patients require such services and the national cancer control program makes an explicit reference to palliative care. India's national AIDS control program makes reference to palliative care but to date no palliative care services for people living with HIV and AIDS have been developed. No state palliative care policies exist in any of India's states and territories, with the exception of Kerala.

**EDUCATION.** The World Health Organization also recommends that countries ensure adequate instruction of healthcare workers on palliative care and pain treatment. Yet, in India official curricula for undergraduate and postgraduate medical studies do not provide for any specific education on palliative care and pain management. According to leading palliative care doctors, out of more than 300 medical colleges, only five in the entire country have integrated some instruction on palliative care into subjects of the official curriculum. While a few teaching hospitals offer rotations in palliative care units for postgraduate students in oncology or anesthesiology, most of these hospitals simply lack such units. As a result, the vast majority of medical doctors in India are unfamiliar with even the most basic tenets of palliative care or pain management.

**DRUG AVAILABILITY.** Finally, the World Health Organization recommends that countries establish a rational drug policy that ensures availability and accessibility of



A 60-year-old palliative care patient with lung cancer at his home in northern Kerala.





A breast cancer patient receives chemotherapy in Hyderabad, while her brother-in-law watches over her.

essential medicines, including morphine. Because opioids are controlled substances globally—and are thus not freely available on the market—ensuring their availability for medical purposes is more complicated than it is for most other drugs. States have an obligation under international law to ensure both the availability of opioids for medical purposes and take steps to prevent their misuse.

While the Indian government, to its credit, recommended in 1998 that states adopt narcotics regulations that create a balance between these two requirements (the Department of Revenue’s “model rule”), two-thirds of India’s states have failed to do so and maintain outdated regulations for opioid

medications that, in the words of India’s own national Department of Revenue, deny “easy availability of morphine to even terminally ill cancer patients” and have caused “undue sufferings and harassment” because they are “often too strict and cumbersome.” Because of these regulations, many hospitals and pharmacies do not want to commit the amount of time it takes to go through the bureaucratic steps required to obtain morphine, and thus simply do not stock it. Others find that the bureaucratic intricacies frequently result in shortages and delays as bottlenecks and red tape interrupt the supply chain.

Policy, education, and drug availability barriers have created a vicious cycle: Because pain treatment and palliative care are not priorities for the government, healthcare workers do not receive the necessary training to provide these



A sixteen-year-old bone cancer patient at the MNJ Institute of Oncology in Hyderabad. Her leg has been amputated at the hip.

services. This leads to widespread under-treatment, including of pain, and to low demand for morphine. At the same time, complex procurement regulations discourage pharmacies and hospitals from stocking and healthcare workers from prescribing it, again resulting in low demand. This, in turn, reinforces the low priority given to pain management and palliative care.

Under the International Covenant on Economic, Social and Cultural Rights, the Indian government has an obligation to take steps “to the maximum of its available resources” to achieve progressively all the rights in that covenant, including the right to health. Therefore the government should ensure

that patients who require palliative care and pain treatment can get access to these health services. In particular, it should formulate a plan for the development and implementation of these services, ensure the availability and accessibility of morphine and other medications that the World Health Organization considers essential, and ensure that healthcare providers receive training in palliative care. The failure of the Indian government to do so violates the right to health.

The right to health also requires a rational and equitable distribution of resources for healthcare services, based on the health needs of the population. The Indian government, however, while investing considerable resources into cancer and HIV services, has failed to make effective provision of palliative care, even though the need for such services is extremely high.



A fourteen-year-old cancer patient in Hyderabad. He takes morphine to control his pain.

Under the prohibition of torture and ill-treatment, the Indian government has a positive obligation to take measures to protect people under its jurisdiction from inhuman or degrading treatment such as unnecessarily suffering from extreme pain. As the UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has noted, “failure of governments to take reasonable measures to ensure accessibility of pain treatment ... raises questions whether they have adequately discharged this obligation.” The fact that many of the government-designated regional cancer centers in India, which treat very large numbers of patients who require palliative care, do not offer it, do not stock morphine, and do not have healthcare workers on staff who have been trained in palliative care, strongly suggests that the Indian government has not taken any such

reasonable measures. It may thus be liable under the prohibition of torture and cruel, inhuman, or degrading treatment for the unnecessary suffering of patients with severe pain and other symptoms at such regional cancer centers.

In order to end this unnecessary suffering, the Indian government will need to recognize the urgency of the problem and take proactive steps. Faced with similar situations, several other countries in Asia and elsewhere have organized meetings at which all relevant parties—health authorities, drug regulators, palliative care groups, and others—have been brought together to develop a comprehensive strategy for developing palliative care services and ensuring access to pain medications. In several countries, these inter-agency meetings have allowed a coordinated and comprehensive approach to removing the various barriers, whether regulatory, educational, or otherwise, that impede that process.

While developing palliative care services and integrating them into the healthcare system is a significant challenge, India has a considerable advantage compared to most other countries in the region. The southern state of Kerala is home to one of the most effective community-based palliative care networks in the world. Outside Kerala there are a number of strong palliative care programs, based both in the community and at healthcare institutions. Nongovernmental organizations, such as the Indian Association of Palliative Care, the Institute of Palliative Medicine, and Pallium India, among others, have developed palliative care courses for healthcare workers and have extensive experience providing such training. Finally, the Department of Revenue's model rule for simplifying access to morphine has already been successfully implemented in several states. The central and state governments urgently need to draw on these experiences to develop effective plans of action that guarantee access to palliative care and pain treatment.

**This report focuses specifically on the poor availability of palliative care services in India. Human Rights Watch, however, fully recognizes the enormous problems that exist with poor availability and accessibility of health services at all levels of care in India, as a result of resource problems, inadequate infrastructure, shortages of medicines, and weak public healthcare services. The fact that this report focuses on a specific area of healthcare does not suggest that government authorities in India do not have an obligation under international human rights law to take reasonable steps to address problems in other parts of the healthcare system.**

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<sup>1</sup> Human Rights Watch interview with Muzaffar Iqbal (pseudonym), Hyderabad, India, March 28, 2008.

<sup>2</sup> Human Rights Watch interview with Raj Ramachandran (pseudonym), Kerala, March 22, 2008.

<sup>3</sup> While palliative care is often associated with terminal illness, it can benefit patients with a much broader group of illnesses or health conditions. Palliative care advocates use the term "life-limiting" illness or health condition to delineate the group of patients who would benefit from the services provided by palliative care, including symptom control, pain treatment, psychosocial and spiritual support and others. A life-limiting illness or health condition is a chronic condition that limits or has the potential to limit the patient's ability to lead a normal life and includes, among others, cancer, HIV/AIDS, dementia, heart, renal, and liver disease, and permanent serious injury.

<sup>4</sup> World Health Organization (WHO), "National Cancer Control Programmes: Policies and Managerial Guidelines, second edition," 2002, pp. 86-87.



A 72- year-old lung cancer patient is cared for by his wife in Kovalam, south Kerala.

# States in which Human Rights Watch conducted field research on palliative care



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# KEY RECOMMENDATIONS

The Indian government and state governments should, in consultation with stakeholders, immediately develop action plans to ensure access to palliative care and pain management nationwide. In particular, they should:

- **Develop national and state palliative care policies and strategies, and identify specific benchmarks and timelines for implementation. These should provide for both the establishment of institution-based and community-based palliative care.**
- **Integrate meaningful palliative care strategies into national cancer and HIV/AIDS control programs.**
- **Mandate basic instruction on palliative care into the curriculum for all medical colleges.**
- **Adopt and operationalize throughout the country the model rule on morphine availability and remove any other regulatory barriers that arbitrarily impede access to opioid medications, while ensuring adequate control to prevent their misuse.**
- **Expand palliative care services to all regional cancer centers and adopt a clear plan of action for the establishment of such services at other cancer hospitals.**
- **Ensure that oral morphine is included in essential medicines lists, and that medications included are available in practice.**

# METHODOLOGY

This report is based on research conducted over a one-year period, including field visits to India in March-April 2008 and February 2009. Our field research was conducted primarily in the states of Andhra Pradesh, Kerala, Rajasthan, and West Bengal. We chose these states because of their different levels of palliative care development and their geographic spread. Additional research was conducted in Delhi (National Capital Territory) and in the state of Uttar Pradesh. We also conducted desk research regarding palliative care availability in various other states.

Over the course of five weeks in the field, Human Rights Watch researchers conducted 111 interviews with a wide variety of stakeholders, including 38 people with cancer, HIV/AIDS patients, and a variety of other life-limiting health conditions; 59 healthcare workers, including oncologists, AIDS doctors, anesthesiologists, palliative care doctors, and administrators of hospitals, hospices, and palliative care programs; and drug control and health officials.

We made a decision, based on ethical considerations, not to interview people who did not have realistic access to basic palliative care and pain treatment services: We felt that it would be unethical to ask people to discuss in detail their pain and other symptoms or their—often terminal—illness if they had no possibility of accessing appropriate professional help. As a result, the patients we interviewed were privileged compared to the average patient with life-limiting disease in India in that they had gained access to palliative care services (although many had experienced long periods without such access and had consequently experienced terrible suffering). The picture that can be construed from our interviews therefore does not fully capture the deprivation and anguish caused by poor availability of palliative care and pain treatment services.

One implication of this decision was that we conducted our research mostly in states and at healthcare institutions with some form of palliative care. In West Bengal, where the dearth of palliative care and pain management provision was particularly

severe at the time, we did not seek to interview any patients, instead focusing on healthcare workers and government officials.

Most interviews with patients were conducted at healthcare institutions such as hospitals and palliative care providers, or in communities at ad hoc outpatient clinics or in palliative care patients' own homes. At healthcare facilities we interviewed both outpatients and inpatients. Where possible, interviews were conducted in private. Interviews were semi-structured and covered a range of topics related to palliative care and pain treatment. Before each interview we informed interviewees of its purpose, informed them of the kinds of issues that would be covered, and asked whether they wanted to participate. We informed them that they could discontinue the interview at any time or decline to answer any specific questions, without consequence. No incentives were offered or provided to persons interviewed. We have disguised the identities of all patients we interviewed in this report to protect their privacy. The identities of some other interviewees have also been withheld at their request.

Interviews with healthcare workers and officials were conducted in English. Most interviews with patients were conducted in local languages—Bengali, Hindi, Malayalam, Rajasthani, Telegu, and Urdu—with the assistance of translators. All translators we used were affiliated with local palliative care programs to ensure that they understood the sensitivities of interviewing patients with serious illnesses as well as the basics of palliative care and pain management.

In July 2009 Human Rights Watch wrote detailed letters summarizing the findings of its research to the Ministry of Health and Family Welfare and the Medical Council of India, inviting them to respond to the findings and offering to present comments in this report. Copies of the letters are included in this report in Annexes 4 and 5. When this report went to print in early October 2009, no responses had yet been received.

All documents cited in the report are either publicly available or on file with Human Rights Watch.