



UPR Submission India November 2011

This submission highlights the serious concerns of our organizations regarding the very limited availability of palliative care services in India. As a result, hundreds of thousands of patients with cancer and other health conditions suffer unnecessarily every year because they cannot get access to effective, safe and inexpensive medications that could relieve their suffering. As we have documented numerous times, the suffering of these patients is often so severe that they want to die rather than live with their pain. In some cases, they even attempt suicide.

This submission focuses on two key issues that we hope will be addressed through the UPR process:

1. The insufficient steps of the Indian government to ensure that effective palliative care is available in all so-called Regional Cancer Centres;
2. The failure of many of India's states and union territories to implement effectively and in a timely fashion simplified regulations for morphine availability recommended by the central government.

Lack of Availability of Palliative Care in Regional Cancer Centres

In an effort to strengthen cancer treatment facilities, the Indian government has designated 29 cancer hospitals around the country as Regional Cancer Centres (RCCs). The government provides considerable financial support to RCCs to improve their provision of cancer services. RCCs are the lead government-supported cancer centers in the country and are supposed to offer comprehensive cancer care to patients. In total, several hundred thousand patients receive cancer care from RCCs every year.

About 70 percent of cancer patients in India are diagnosed when their cancer is advanced and they are unlikely to still respond to curative treatment; most can only still benefit from palliative care and pain management. Indeed, an estimated 80 percent of these patients will develop moderate to severe cancer-related pain for an average of about 90 days.

In a 2009 report (attached), “Unbearable Pain: India’s Obligation to Ensure Palliative Care,” Human Rights Watch extensively documented the suffering these people face when they do not have access to palliative care and adequate pain treatment.¹ Many of these patients expressed a sentiment commonly expressed by victims of police torture: They would do anything to make the pain stop. Many patients told Human Rights Watch that their pain was so severe that they would prefer to die than have to live with it.

Yet, more than half of India’s RCC do not offer any palliative care or pain management. Of the 29 RCCs, 10 are known to have effective palliative care programs that cover a significant percentage of the need and 5 offer some limited palliative care. The rest appear to offer no palliative care or effective treatment for moderate to severe pain at all.

To date, the Indian government has failed to use its considerable leverage over RCCs to ensure that they offer palliative care. It could have made the designation as RCC conditional on them developing palliative care services; earmarked funding specifically for palliative care; or organized training seminars for RCC staff on palliative care. The government has failed to implement the recommendations of a palliative care task force appointed by the Ministry of Health and Family Welfare in 2005 in the context of the development of its 2007-2011 national cancer control plan. This task force recommended that a palliative care unit be created at all RCCs. (A copy of the task force recommendation is included in Human Rights Watch’s report.) This failure results in many tens of thousands of patients each year being unnecessarily abandoned to severe pain and suffering.

Failure to Ensure Implementation of Simplified Regulations for Morphine

In 1985, the Indian government enacted the Narcotic Drugs and Psychotropic Substances Act (NDPS Act). The Act and the implementing regulations that India’s states and union territories adopted, led to the collapse in the country’s use of medical morphine. Hospitals and pharmacies stopped stocking the medication because of punitive provisions in the Act and highly burdensome licensing procedures in state regulations. Over the next decade, morphine consumption in India dropped by 97 percent, depriving hundreds of thousands of patients of access to strong analgesic medications that they required for pain relief.

In 1998, after it became aware of the dramatic impact the NDPS Act and state regulations were having on patients with pain, the national Department of Revenue drafted a “model rule” that it recommended states use to simplify their rules for medical use of morphine. In a letter to all states and union territories, the Department stated that existing regulations denied “easy availability of morphine to even terminally ill cancer patients,” and caused “undue sufferings and harassment” because there were “often too strict and cumbersome.”

¹ See Human Rights Watch, “[Unbearable Pain](http://www.hrw.org/en/reports/2009/10/28/unbearable-pain-o): India’s Obligation to Ensure Palliative Care,” October 2009, available at <http://www.hrw.org/en/reports/2009/10/28/unbearable-pain-o>.

Despite this crucial recommendation by the Department of Revenue, 13 years later just fourteen of India's 35 states and union territories² have implemented the model rule, and several of those have done so in a way that has created new burdensome procedures that continue to deter pharmacies and hospitals from stocking the medication. As a result, hundreds of thousands of patients facing severe pain in many states continue to be unable to get access to morphine.

Access to Palliative Care and Human Rights

Palliative care is a health service that focuses on improving the quality of life for patients with incurable or life-threatening illnesses. The World Health Organization considers it 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.³

Under the International Covenant on Economic, Social and Cultural Rights, governments have 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 the highest obtainable standard of health. Therefore governments should ensure that patients who require palliative care and pain treatment can get access to these health services. In particular, they 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. Failure to do so violates the right to health.

Under international law, governments have an obligation to take measures to protect people under their 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."⁴

² Andhra Pradesh, Arunachal Pradesh, Dadra and Nagar Haveli, Delhi, Goa, Haryana, Jammu and Kashmir, Karnataka, Kerala, Madhya Pradesh, Mizoram, Orissa, , Sikkim, Tamil Nadu, and Tripura.

³ World Health Organization (WHO), "National Cancer Control Programmes: Policies and Managerial Guidelines, second edition," 2002, pp. 86-87.

⁴ 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 January 16, 2009).

Recommendations

The lack of availability of palliative care in most of India's regional cancer centers and the failure of most of India's states and territories to implement the simplified drug regulations recommended by the central government are inconsistent with the government's obligations under the right to health and prohibition of torture and other cruel, inhuman or degrading treatment. We believe the Indian government should be asked to:

1. Take immediate steps to ensure that all regional cancer centers in India offer palliative care, stock oral morphine, and have healthcare workers trained in its use.
2. Take immediate steps to ensure that all states and union territories that have not yet done so implement the "model rule" as recommended by the central government in 1998.