

Introduction

They are afraid of getting morphine into hospitals because of the fear of addiction and stigma around the medical use of opioids. Some doctors call it 'the collateral damage of the war on drugs'.

leaves patients to die in pain

Dr Savita Butola, palliative medicine specialist from the Border Security Force

Across the world – and predominantly the Global South – people are dying in pain because they are denied access to pain relief. In 2015 the Lancet Commission on Global Access to Palliative Care and Pain Relief estimated that more than 61 million people experienced serious health-related suffering.¹

The World Health Organization (WHO) regards morphine as the first line of treatment for moderate-to-severe pain in terminal illnesses such as cancer. It is effective and cheap. Yet the majority of people who need it do not have access to it. Restrictive drug policies stemming from the so-called 'war on drugs' are partly to blame for this. This is an issue of inequality, and one that is growing with an ageing population.

This is illustrated clearly in India's opioid paradox: the country is among the largest opioid medicine producers, yet its patients die in pain.

This case study draws on small scale researchⁱ conducted by Health Poverty Action and looks at the impact of drug policy on access to opioid based pain relief in three states in India (Delhi, Punjab and Gujarat). It explores the lack of availability of opioid pain relief and its impacts on palliative care medical staff, patients and their family members.

Our findings which reflect themes found in other research on this issue, found that:

- Restrictive drug regulations and bureaucratic barriers discourage institutions and medical practitioners from obtaining and/or maintaining licenses for opioid medicines.
- Inadequate training and education in palliative care and pain management allows misinformation and stigma about opioid based medicines to flourish, severely impeding end-of-life-care for patients.

These result in the denial of essential medicines to patients and fuel inequality and poverty in the country.

This is yet another example of how repressive drug polices undermine international development and the Right to Health. This is an issue which the international development and global health communities must address with urgency.

i. The researchers Sebastian Soto and Aron Suba, conducted 29 in-person interviews including with 12 patients (and their family members present during the interviews), and with 17 health professionals in five hospitals in the states of Gujarat, Punjab and Delhi.

Background: The global denial of opioid medicines

The richest 10% of the world's population receives almost 90% of the morphine distributed worldwide. Between 70 and 85% of patients with serious health-related suffering live in countries where even oral morphine is largely unavailable.² These inequalities are widening. From 2015 -2050, the number of people aged 60 or over is projected to more than double, and the number of people over 80 more than triple.³

The Sustainable Development Goals (SDGs) (in Target 3.5) call for strengthened "prevention and treatment of substance abuse, including narcotic drug abuse" yet are silent on the issues of palliative care or pain relief. Despite palliative care being recognised as an essential part of universal health coverage, the global health and international development communities are largely silent on the impact of the so-called 'war on drugs' on access to pain relief.

India

India is one of the world's top producers of opium for the legal medical market globally (ranked number four by The International Narcotics Control Board INCB).⁴ It is the only country that legally produces opium gum which houses several indispensable alkaloids such as morphine, codeine and thebaine. Morphine is known to be one of the best analgesics in the world, providing relief in extreme and excruciating pain.⁵ Opium cultivation is permitted in certain areas in the states of Madhya Pradesh, Rajasthan and Uttar Pradesh.⁶

Despite this, India reveals a deadly paradox: it's availability of essential opioid analgesics such as oral morphine is among the lowest in the world.

In India, terminal illnesses are on the rise. Cancer is an increasing cause of mortality in the global South. In India, more than 1 million cases of cancer were diagnosed in the year 2014 and this figure is expected to increase to 1.7 million by 2035. The vast majority of cancer is detected at a late stage meaning treatment options are limited. As a result, the cause of death in such cases are rising with nearly 700,00 people dying from cancer in India in 2014.

Despite the announcement of a national programme for palliative care in November 2012, and a 2014 amendment to the Narcotic Drugs and Psychotropic Substance Act recognising the need for pain relief as an important obligation of the government, patients in India are still being denied access to pain relief. The amount of morphine available to palliative care patients in India in need of pain relief is only enough to meet 4% of the need.¹¹

According to data from the Lancet Commission on Pain Relief and Palliative Care, India has 43 milligrams of morphine per patient in need of palliative care, meaning 96% of need goes unmet. In contrast Canada, which has the highest levels of access, has 68,194 milligrams (3090% of what is needed) per patient. 12



Drug policy drives inequality

Our research found the following impacts of inequitable access to pain relief:

Geographical inequality

In Punjab which also has a high percentage of people with problematic drug use and trafficking, the availability of opioid analgesics is worse than Gujarat and New Delhi. As a result, many of the patients we interviewed in this state travelled large distances, sometimes to other states to receive treatment.

Health professionals at All India Institute Of Medical Sciences (AIMS) hospital in Delhi estimated that around 50% of their patients travel from other states such as Punjab and Haryana. Similarly, in one hospital in Gujarat, more than 80% of the patients came from other cities traveling long distances to access care. Dr Sushma Bhatnagar from AIMS hospital in Delhi cited the main reason for these disparities between states as the stigma and lack of knowledge among policy makers and health professionals with respect to morphine and opioid-based medicines.

Public/private inequality

Our research found that morphine and fentanyl are relatively easily available in the private sector. In India, Fentanyl patches, the most popular semi-synthetic opioid analgesic, cost 6-10 times more than oral morphine (and are as not as effective). Because of their high prices, semi-synthetic drugs are mostly available in private health facilities. This divide between the public and private spheres makes these inaccessible to those who cannot afford private care.

Financial inequality

Approximately 22% of India's population (269 million people) live below the poverty line. ¹⁴ The poor are more likely that the rich to die of cancer, making this an issue of equity. Our research highlighted the multifaceted and severe socio-economic impacts of the limited availability of essential opioid medicines on patients who need them. Often many patients would travel hundreds of kilometres to access medication to control their pain.

Most of the patients come from outside of Ahmedabad. 70-80% of our patients come from a very poor background...
The patients who come for morphine only for treating their pain often travel a lot, and that is a big stress factor for them.

Dr. Tanvi Vyas, Clinical and Community Psychologist from Gujarat Cancer and Research Institute Regional Cancer Centre (GCRIRC), Ahmedabad

Cost of travel is another challenge. Whilst some cancer patients were financially supported by government subsidies, this was not sufficient to prevent poverty. Even when palliative care services and medications are offered free of charge, travel costs drive them deeper into debt. Terminally ill patients are usually accompanied to hospital by their family members who are their care givers, which can result in loss of income for the entire family.¹⁵

My family accompanies me for the treatment and it costs INR 3,200 (£34) every month to come here by train. Our family's income altogether is only INR 5,000 (£54) monthly however. We cannot pay for these travel costs from our income, so we had to take loans. In Rajasthan it is not possible to get the morphine that takes away my pain. My son here also had to quit his job to take care of me, it is very bad.

Cancer patient from Rajastan, forced to take a 10 hour journey to hospital each month

ii. In Gujarat there are four pharmaceutical companies producing opioid analgesics that makes it easier for medical institutions to procure the drug. In Delhi's All India Institute of Medical Sciences (AIIMS), strong, medium and weak opioids are available to all cancer patients for free. Morphine is available only in three governmental medical institutions in Punjab, located in the cities of Patiala, Sangrur and Chandigarh.

Impact on families

The research found instances in which children had to leave school and were forced into work to support the needs of their family in times of emotional and financial stress, as well as being left in danger, even facing sexual violence.

I have been having very strong pain since this January. I travel to receive treatment for my disease and now also to ask for the prescription for morphine from a village that is 450 kilometres away from here. My husband is a labourer in construction works, but he quit his job to take care of me, so we had to take a loan. I have three children aged 16, 12 and 10, and the two oldest stopped going to school to go to work as a labourer so that the family can pay back the loans.

37 year old terminally ill patient with an advanced stage of mouth cancer, Gujarat

care of the children and the rest of the family is just left behind at home. The children are left doing their own cooking.... And there have been burnt patients because young children got into the kitchen and got themselves burnt... And there is no place, you know, where you can leave young girls safely. We have had children molested because they were staying alone in the village.

Dr Savita Butola, palliative medicine specialist from the Border Security Force, formerly posted in Punjab

Severe pain accompanied by financial stress, which is caused by a lack of access to essential medical opioid analgesics led to psychological problems for both patients and their family members.

This echoes the findings of the Lancet Commission's report on the global situation. The Commission found, in addition that the impact on families exacerbates gender inequality, due to the burden of care.

The role of the war on drugs in denying pain relief

In many countries in the Global South unduly restrictive laws and regulations hinder the availability of and access to opioids for people who need them.¹⁶

The inadequate access to morphine for people in LMICs with a medical need is the result of obstacles in demand and supply in countries that have falsely linked local, medical access with national and international non-medical use.

Lancet Commission on Global Access to Palliative Care and Pain Relief

The participants in our research highlighted several reasons for a lack of access to opioid pain relief. This included a lack of incentive for big pharmaceutical companies. Morphine's low cost means it generates little profit for pharmaceutical companies, especially when compared to the increasing availability of patented semi-synthetic opioids for the private sector.

Aside from this two main reasons that explicitly link to drug policy were found:

Opiophobia

Opiophobia is the stigma or exaggerated concern about the risks associated with opioids preventing their appropriate medical use. We found that opiophobia manifested itself in two main ways, reflecting what is often cited globally:

Restrictive regulations

Tedious complex procedures at institutional levels made it difficult for hospitals to acquire licenses for morphine, whilst at the same time the fear of severe penalties for minor clerical mistakes were a barrier to practitioners applying for or maintaining them.

India's Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985 (amended in 1988 and 2001) enacted regulations to prevent usage and circulation of misused substances. The law allows state governments to permit and regulate the manufacture and possession of medicinal opium. After the adoption of the Act,

morphine consumption in India dropped exponentially by 97% reaching a low of 18kg in 1997.¹⁷ Research conducted by the WHO Collaborating Centre for Policy and Communications in Cancer Care¹⁸ categorically cited two reasons for this decline: the 10-year mandatory minimum prison term for violations involving narcotic drugs established by the Act; and cumbersome licensing procedures of import, export and transport between states, that led to pharmacies all over the country dropping morphine from their stock.¹⁹

Our research exposed instances in which medical practitioners gave up licenses and stopped stocking morphine due to the bureaucratic burden and fear of being held liable.

"I used to procure, prescribe and dispense opioid analgesics for palliative care in my private practice. This license included a license for morphine. I have kept this license for around 12 years, however, later I stopped the license as it was bureaucratically very burdensome to have and it also came with a lot of added responsibility for which I could have been held liable. Even for making minor administrative mistakes they could have come and raid my private clinic within the institution, and I could be put behind bars. This was a lot of pressure and I could get into trouble for having these medicines. Having a license comes with a lot of stress and risks. This was a trouble I didn't need. Maintaining all these form and administration for opioids also took up a lot from my time."

Dr D. G. Patel, Private practitioner within GCRIRC, Ahmedabad

"There are a lot of stakeholders that need to be involved for getting a license for a health institution to procure and store morphine for pain management. After an institution receives a license for procuring, storing and dispensing morphine to patients, they must abide by very stringent and bureaucratically burdensome regulations. The drug inspection authorities can also hold criminal charges on hospitals and doctors if there are any small bureaucratic mistakes in the records. There are very little incentives for all these stakeholders to sit together and to arrange a license for a health facility... Once a memorandum of understanding is signed by all these parties for a license for procuring morphine by the health facility, this must be renewed usually every 1-2 years again. Then the hospital would have to go through the same long process of receiving a license".

> Dr. Vibha Mahayian, anesthesiologist, Tegor Hospital, Jalandhar, Punjab

Stigma due to lack of training

Palliative care is not a part of the mainstream medical curriculum in India. As a result, doctors and nurses are commonly not aware that opioid medicines such are morphine are effective and inexpensive drugs for controlling extreme pain among the terminally ill.²⁰ Palliative care experts we interviewed noted that the lack of training of health practitioners has become a major barrier to alleviating unnecessary suffering.

Interviews with health practitioners confirmed that the perception of stigma on the use of opioid analgesics affects the availability of adequate pain management for patients during end-of-life-care.

My experience in general outside this institution – where everybody receives training on palliative care and opioid analgesics – is that medical professionals are afraid of using opioid analgesics for the treatment of pain. They are afraid that the medicines would lead to addiction in the patients receiving palliative care or that the medicines would get misused.

Dr. Geeta Joshi, former Head of the Department of Pain and Palliative Medicine, GCRI, Ahmedabad, presently working in a community oncology centre

Education and adequate intervention programmes can address this. Some progress has been made in this regard. As a radiation oncologist from Punjab also noted "Earlier the main perception was that opioid analgesics should not be used because they are addictive. Slowly, these perceptions are changing due to a lot of awareness raising workshops and programmes. There is still fear among health professionals however, that strong opioid-based medicines cause respiratory depression."

Lack of appropriate training and education in palliative care not only affects pain management by doctors, but also fuels the stigma surrounding addiction making doctors hesitant to prescribe opioid based medicines.

Conclusion and recommendations

Known as the so-called 'war on drugs', prohibition has not only failed to achieve its goals, but has fuelled poverty and undermined the health of people across the world. In this case of those suffering from terminal illnesses. In parts of India this failed war is forcing patients to leave their jobs, live in debt and travel long distances just to access medicines, compounding poverty. The social and economic impact of the limited availability of pain relief exacerbates the situation for those already suffering from extreme pain.

Addressing this requires changes in both policy, and raising awareness, adequate training and behavior change among the medical community and the wider population at large.

This is possible. Kerala, a southern state in India provides a good case study for palliative care in the country. Home to 841 of India's 908 palliative care sites, Kerala has one of the largest networks of palliative care in the world. In 1993 only two clinics in Kerala, both attached to cancer hospitals, dispensed oral morphine. As of 2014, 170 institutions stocked and dispensed it. Civil society – alongside a responsive and supportive state government – has been widely credited as a driving force behind Kerala's success. Jamaica, Nepal, Vietnam, and Mexico have also driven success in removing barriers to accessing opioid pain relief.

In many cases civil society have been the pioneers in making progress in palliative care. The global health and international development communities can champion palliative care as a core part of Universal Health Coverage, including advocating for extending access to medicines, ensuring appropriate guidelines for pain relief, training and capacity building for primary care providers and advocating for audits to identify and subsequent removal of regulations that impede to access to opioid medicines.²³

Beyond this, advocating for the failed 'war on drugs' to be replaced with polices which support health and rights is something that the international development and global health communities must address with urgency.

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