

# Barriers to cancer pain relief: an international perspective on drug availability and service delivery

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## KEY LEARNING POINTS

- Cancer pain remains unrelieved, particularly in resource-poor settings, worldwide.
- The main barriers to cancer pain relief are lack of opioids, inadequate education, and government indifference to the issue.
- The principle of “balance” is essential in opioid regulation.
- Cancer pain and palliative care services across the world remain weakly developed and have limited coverage.
- Cancer pain and palliative care services must be locally appropriate and sustainable.
- Awareness of, and engagement with, issues is essential for all with an interest in achieving a cancer pain-free world.

## INTRODUCTION

Around the world, cancer is increasing and it is having a differential impact in poorer countries. Of the estimated ten million people<sup>1</sup> who are diagnosed every year, over half are living in the developing world and many will have incurable disease at the time of diagnosis. By 2020, it is estimated that the incidence of cancer will double.<sup>2</sup> The global burden of cancer will increase from 10 to 24 million over the next 50 years and 17 million of these will be in developing countries.<sup>3</sup>

Cancer pain is common. Two-thirds of those with advanced disease, and a third of those undergoing active treatment, suffer pain.<sup>4</sup> Until earlier referral and diagnosis occur and standard therapies are able to be deployed for the majority of those with cancer, pain relief and palliative care will remain the most relevant provision for large numbers

affected. Meanwhile, both cancer and palliative care remain relatively low priorities on the global health agenda.<sup>5</sup>

In this chapter, we examine how cancer pain has developed as a field of interest, going on to highlight the particular problem of drug availability. We describe in detail the work of the Pain and Policy Studies Group in Wisconsin, USA and show how its research and development program is having an impact on opioid availability in a number of different countries and resource settings.<sup>6</sup> In order to gain a better understanding of related service developments, we also draw on studies undertaken by the International Observatory on End of Life Care at Lancaster University, UK as part of its global development program.<sup>7</sup> The chapter contains a number of case studies and illustrations that highlight the barriers to cancer pain relief, as well as some of the approaches that have been found to overcome these.

Before the 1970s, cancer pain had received little international attention as either a clinical or a public health problem and was often regarded as an inevitable, not fully controllable, consequence of the disease.<sup>8,9</sup> The spread of modern hospice and palliative care and the creation of the professional field of pain studies encouraged a small number of pioneering oncologists to organize the first International Symposium on Cancer Pain, held in 1978.<sup>10</sup> Research presented at this and subsequent conferences suggested that physicians had the means to relieve even severe cancer pain and that the principal factors contributing to poor pain management were legal barriers against opioid use and poor dissemination of available knowledge about pain management. In 1982, the World Health Organization (WHO) enlisted the aid of palliative care leaders, cancer pain specialists, and pharmaceutical manufacturers to develop a global Programme for Cancer Pain Relief, based on a three-step analgesic ladder with the use of adjuvant therapies, and incorporating the use of strong opioids as the third step.<sup>11</sup> WHO representatives launched an international initiative to remove legal sanctions against opioid importation and use, relying on national coordinating centers to organize professional education and to disseminate the core principles of the pain management. The WHO programme met with only partial success, however. Opioid consumption between 1984 and 1993 rose dramatically in ten industrialized countries, but showed much smaller increases in the rest of the world<sup>12</sup> and significant differences in the pattern and the extent of opioid use continued to be observed within and between global regions.<sup>13</sup>

Effective management of cancer pain needs to be multifaceted and should be informed by the concept of “total pain,” as described by Cicely Saunders, founder of the modern hospice movement, with its recognition of the physical, psychological, social, and spiritual dimensions of pain.<sup>14</sup> Drug treatment, however, remains the mainstay of cancer pain relief. Since 1986, the WHO analgesic ladder<sup>15</sup> has provided a deliberately simple framework for the progressive treatment of malignant pain.<sup>11</sup> Its originators hoped it would lead to a world free of cancer pain, though they acknowledge now that this has not come to pass.<sup>16</sup> There are many reasons for this, including reluctance on the part of physicians to prescribe strong opioids, fear among healthcare professionals and the public about addiction and abuse, lack of state and national government engagement with the issue of cancer pain, and a lack of availability of essential drugs due to stringent regulation and economic factors.

Recognition of these issues led the WHO to develop its concept of “foundation measures” to promote the implementation of cancer pain relief programs. These highlight the importance of three key factors essential if cancer pain is to be overcome: education, government policy, and drug availability.<sup>4</sup>

Education needs to be wide ranging to achieve these aims. Clearly, healthcare professionals must be trained in

the appropriate and safe use of analgesic drugs, particularly opioids, but this can be difficult if the dominant culture in their workplace is to view these as dangerous drugs of misuse. Education, therefore, needs to begin by addressing these fears. Paradoxically, a useful starting point for these discussions is the Single Convention on Narcotic Drugs 1961 (amended 1972) which recognized “... that the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering.”<sup>17</sup>

Policymakers, drug regulators, and the general public also need to be more aware that opioid drugs, such as morphine, have an essential place in the management of pain – one that cannot be sacrificed because of any potential for diversion and misuse.

Government policy, whether at state or national level, has to recognize and emphasize the importance of the effective management of cancer pain, which should be seen as a priority. Similarly, the availability of essential drugs is crucial in efforts for the relief of pain in cancer. In some regions of the world, access to appropriate drugs is taken for granted, but in many more these are simply unavailable. The reasons for this are complex, but engagement with them is essential for anyone who concurs with the vision of a world free of cancer pain. As Liliana de Lima, of the International Association for Hospice and Palliative Care (IAHPC) has reflected:

In so far as improving access to opioids is an international effort, we are all affected to some degree by the decisions and actions taken by others. We need to become aware that opioid availability is not just a local issue, but rather one with no borders. All stakeholders in this process, including patients, professionals, multilateral organizations, the pharmaceutical industry, policymakers, and healthcare professionals, need to be included in the development of strategies to improve this situation.<sup>18</sup>

## DRUG AVAILABILITY

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Key to the effective implementation of the WHO analgesic ladder is the availability of the medication necessary at each of the three steps. It is both fruitless and frustrating for practitioners to be trained in the effective management of pain and to then lack the tools to implement that knowledge. Economic factors can sometimes limit the availability of analgesics recommended on the first two steps of the ladder but, in reality, it is the lack of the step three analgesics, principally morphine, which results in the most suffering. The major reason for this is regulation and its interpretation.

The Single Convention on Narcotic Drugs<sup>17</sup> is an international treaty that seeks to ensure that all United Nations (UN) member countries take steps to prevent the abuse of narcotic drugs while ensuring adequate

availability for medical and scientific use. Derived from the Greek *narke* (numbness)<sup>19</sup> narcotics are, essentially, substances which induce drowsiness. The term “narcotic drug” however, has a legal significance denoting any substance, natural or synthetic, listed in schedules I and II of the 1961 Convention. The International Narcotics Control Board (INCB) was created by the convention for its implementation. The remit of the Single Convention is to promote governmental compliance with the treaties.

Currently, the Single Convention exercises control over 116 narcotic drugs. These are grouped into four schedules depending on their therapeutic effectiveness and propensity for misuse, with Schedule I drugs, such as morphine, fentanyl, and opium, subject to the most stringent controls. The WHO is charged with assessing whether the list should be added to or amended. States that are signatories to the Convention agree to implement its terms locally and to cooperate with other states in achieving its aims, principally to ensure that the production, trade, and distribution of narcotic drugs is properly managed and is for scientific and medical purposes only. They must also recognize the authority of the international control organs: the Commission on Narcotic Drugs of the Economic and Social Council and the INCB.

The commission is concerned with all aspects of the Convention, particularly with respect to amending the schedules, identifying issues relevant to the functions of the INCB, and communicating with parties outside the convention to encourage adoption of similar measures.

The board consists of 13 members including three with a medical, pharmacological, or pharmaceutical background from a list of at least five nominated by the WHO. The remaining ten are elected from a list compiled by both members and nonmembers of the UN. They serve for five years. Each year, states must provide the board with estimates of their drug requirements and statistics related to the production and consumption, import and export, seizure and disposal, and stocks of drugs, as well as details of areas where the opium poppy is cultivated. Using these data, the manufacture and importation of each drug is limited depending on the sum of the quantities that are:

- consumed for medical and scientific purposes;
- used for the manufacture of other drugs not covered by the Convention and those in Schedule III;
- exported;
- added to the stock to bring it to the level of the relevant estimate;
- required for special purposes, within the limit of the relevant estimate.

Countries where the opium poppy is grown also need to establish a national opium agency which designates areas for cultivation and licences the producers. Licences are also needed for the manufacture, trade, and distribution of drugs, except when this is carried out by a state

enterprise. Medical prescriptions are required for the supply of drugs, unless legally available over the counter and, if deemed necessary, Schedule I drugs may need to be prescribed on official forms. Export of drugs is forbidden unless in accordance with the laws of the importing country and within the estimates of need for that country. Complicated arrangements exist for import and export to happen. Organizations and professional individuals utilizing the drugs therapeutically are required to keep scrupulous records and governments must ensure illicit traffic is avoided.

Given the level of control exercised over narcotic drugs, it is not difficult to understand why some, from healthcare practitioners through to national governments, make the decision that obtaining and prescribing these drugs is too onerous. Because of the potential for abuse, regulation is necessary, but this can exist in harmony with adequate supplies for medical need. Indeed, the INCB is committed to assisting governments to achieve a more balanced approach<sup>20</sup> as the following examples illustrate.

### Regulation in Italy

Towards the end of the 1990s, the INCB became increasingly troubled about the low levels of morphine consumption in Italy, a country with a relatively high per capita income. Indeed, the INCB annual report for 2000 stated:

The Board remains concerned about the low levels of consumption of morphine for medical purposes in Italy, which may be indicative of insufficient availability of the drug for pain management purposes.<sup>21</sup>

Efforts had been made to address the problem with little success, until 1998 when a study<sup>22</sup> revealed that, although lack of physician education and cultural prejudices were implicated in the problem, there were major difficulties related to the prescribing of drugs. The necessary piece of documentation, the Special Prescription Form (SPF) was complex, with three parts, and the amount that could be supplied was strictly limited. In addition, physicians and pharmacists were liable to severe penalties in the event of any technical error. These factors, it was postulated, dissuaded doctors from prescribing the necessary drugs to combat pain effectively. As a result of the study and through new legislation, a simplified prescription was developed which required that the necessary information be entered only once in a way which bore more resemblance to the standard Italian script, thus decreasing any stigma related to the prescribing of opioid medication. The maximum supply available on one prescription increased from eight days to one month and sanctions against physicians and pharmacists became more lenient. With these measures, and an enlightened program of physician and public education about cancer pain funded

by the Drug Department of the Italian Ministry of Health, the basis for a more relevant and appropriate approach to the management of cancer-related pain in Italy has been established.

## Regulation in India

In India in the early 1980s, increasing medical use of opioids gave rise to fears about diversion and drug misuse. The 1985 Narcotic Drugs and Psychotropic Substances Act was passed in response. The Act established new licencing requirements, with states developing their own procedures to conform to the law. The procedures became so complex that institutions seeking to purchase morphine from a neighboring state required five different licences from two different departments in each state, which took time and energy to procure, and all of which had to be valid for shipment to proceed. The result was that physicians and hospitals stopped trying to obtain these drugs and India's consumption of morphine fell by 97 percent between 1985 and 1997. The INCB recognized that this decline indicated that opioids were no longer available for legitimate use and charged the Indian Government with the responsibility to tackle the problem. A WHO demonstration project in Kerala, India, was able to show that when prescribing practices, stock security, and record maintenance were scrupulous, making opioids available for cancer pain did not lead to diversion or misuse.<sup>23</sup> Armed with this information, practitioners from the demonstration project, the Pain and Palliative Care Society, and the Indian Association for Palliative Care were able to lobby state and national government officials into a commitment to maintain a minimum stock of morphine for medical use. In the meantime, many patients had suffered unnecessary pain witnessed by Professor Rajagopal, from the demonstration project:

To communicate the intensity of the dread felt by staff and patients when a morphine shipment was delayed and the joy when the morphine finally arrived is not possible.<sup>23</sup>

## THE PRINCIPLE OF BALANCE

The principle of balance is a concept that applies to ensuring that opioid analgesic drugs are available for legitimate medical use, notably pain relief, whilst preventing their diversion for illicit purposes. The idea has been developed by David Joranson and colleagues at the Pain and Policy Study Group (PPSG), Madison, WI, USA. Joranson's work has been important and influential in the field and, although we highlight some of the work here, readers are directed for further detail to the PPSG website, which is an invaluable resource.<sup>6</sup>

The Pain and Policy Studies Group was established by Joranson in 1996. The group is part of the University of Wisconsin Comprehensive Cancer Center within the School of Medicine and Public Health. It investigates national and international opioid policy and has developed guidelines and undertaken workshops essential to the implementation of any meaningful change in government policy. To date, the PPSG has provided technical assistance to governments and nongovernmental organizations in Africa, Asia, Europe, and Latin America. As a WHO Collaborating Center, it began in 1998 to develop guidelines for governments to assess their opioid regulation policies. An international working group of experts was convened to review these guidelines, including representatives from Italy, China, India, Nigeria, Japan, Saudi Arabia, and the Americas. This resulted in the WHO document *Achieving a balance in national opioids control policy: guidelines for assessment*,<sup>24</sup> subsequently endorsed by the INCB,<sup>25</sup> and which consists of a self-assessment checklist of 16 guidelines within three areas:

1. assessing national policy;
2. estimating annual opioid requirements;
3. ensuring an effective system for distributing drugs to patients.

The guidelines, which are available in some 14 languages, also emphasize the importance of regulators, governments, and practitioners working together to achieve a balanced approach to regulation and availability.

Having developed the guidelines, the next step was to put them into action. To simply send them to the relevant national regulators was unlikely to produce rapid results so the team developed a workshop approach, bringing together both regulators and clinicians to consider the guidelines within their own local contexts. The first of these workshops was held in Quito, Ecuador in 2000, with representatives from Peru, Bolivia, Chile, Venezuela, Ecuador, and Colombia. A follow-up meeting in 2002 found evidence of progress: Venezuela had held a national workshop to highlight the importance of opioid availability and, in Colombia, a National Network of Pain Relief charged with educating doctors in the appropriate medical use of opioids had been established.<sup>26</sup> There was, however, evidence to support the impression that achieving policy change was a long process with much patience and perseverance required.

The case of Romania illustrates that through this approach, along with enthusiasm, determination, and support, tangible changes can be made to government policy on opioid availability. In 2002 the PPSG, in collaboration with the WHO regional office and the Open Society Institute, held one of its workshops in Budapest, Hungary attended by representatives from Bulgaria, Croatia, Hungary, Lithuania, Poland, and Romania. Romania was chosen as a pilot country for follow up. It had very restrictive policies on the use of opioids, which

dated from more than 35 years earlier at the time of the Ceausescu regime. Yet, within its pioneering palliative care services, there were healthcare professionals who were highly motivated to lobby for and to initiate change<sup>27</sup> and within the Ministry of Health there was a willingness to engage with the issues. The ministry established a Commission of Specialists in Pain Therapy and Palliative Care, charged with identifying and clarifying the main barriers to effective cancer pain relief in Romania. This group worked closely with the team from the PPSG which undertook a comprehensive review of the country's existing regulations and, in summer 2003 presented its recommendations for change to the Ministry of Health. These recommendations included the removal of government restrictions on the maximum doses of opioids and simplification in the process of drug authorization for longer-term prescribing. They also requested that more than one opioid could be prescribed on one form and that change in drugs and doses could be determined by patient need. The Ministry of Health was also asked to clarify various points about effective record keeping, responsibility for submission of statistics to the INCB, and which opioids were to be licenced for importation and manufacture in Romania. In addition, the ministry was asked to make the effective management of cancer pain a high priority and to work with the Ministry of Education to ensure pain treatment formed an integral part of the training of health professionals. Drafting new legislation based on the recommendations then started and, whilst this proved challenging for all involved, the proposed law passed both houses of the Romanian parliament in November 2005. As Daniela Mosoiu, hospice physician and a key figure in effecting the changes commented:

We hope that the Romania project will serve as a positive example of how an outdated and restrictive national antinarcotics law can be reformed into one that embodies the essential principle of balance, retaining essential control over the security and distribution of controlled drugs, while allowing physicians to practice modern pain medicine and care for their patients.<sup>27</sup>

## PATTERNS OF SERVICE DEVELOPMENT

Just as innovations in cancer pain relief began to get underway from the 1970s onwards, significant strides were also being made in the global development of palliative care, which in many areas had a strong emphasis on the care of patients with cancer and gave attention to the effective management of pain and other symptoms. It was the work of Dr Cicely Saunders, first developed in St Joseph's Hospice in Hackney, east London that was to prove most consequential, for it was she who began to

forge a peculiarly modern philosophy of terminal care. Through systematic attention to patient narratives, listening carefully to stories of illness, disease, and suffering, she evolved the concept of "total pain".<sup>14</sup> This view of pain moved beyond the physical to encompass the social, emotional, even spiritual aspects of suffering – captured so comprehensively by the patient who told her, "All of me is wrong."<sup>28</sup> However, it was also linked to a pragmatic approach to pain management. Her message was simple, "constant pain needs constant control."<sup>29</sup> Analgesics should be employed in a method of regular giving which would ensure that pain was prevented in advance, rather than alleviated once it had become established; and they should be used progressively, from mild, to moderate to strong.

Having established the modern science and art of caring for patients with advanced malignant disease, Cicely Saunders went on to found the world's first modern hospice, combining clinical care, teaching, and research at St Christopher's in south London, which opened in 1967. Immediately it became a source of inspiration to others and was also firmly established in an international network. The correspondence of Dr Saunders shows clearly how it attracted the interests of clinicians from many countries who were eager to develop their practical skills through work on the wards of the hospice.<sup>30</sup> It quickly sought to establish itself as a center of excellence in a new field of care. Its success was phenomenal and it soon became the stimulus for an expansive phase of hospice and palliative care development, not only in Britain, but also around the world.

From the outset, ideas developed at St Christopher's were applied differently in other places and contexts. Within a decade it was accepted that the principles of hospice care for cancer patients could be practiced in many settings: in specialist inpatient units, but also in home care and day care services; likewise, hospital units and support teams were established that brought the new thinking about the care of those with advanced malignant disease into the very heartlands of acute cancer medicine. Modern hospice developments took place first in affluent countries, but in time they also gained a hold in poorer countries, often supported by mentoring and twinning arrangements with more established hospices in the west. By the mid-1990s, a process of maturation was in evidence in some countries, but elsewhere growth was slow and a source of disappointment to palliative care activists.

Yet all around the world there are examples of innovative services seeking to address the problem of cancer pain. The difficulties they face in achieving their goals are complex in character and can be found in rich and poor countries alike. Close working relationships within the field of palliative care have been important to success in many places and the efforts of pain specialists interested in malignancies have also been vital. Drawing on studies undertaken by the International Observatory on End of

Life Care (IOELC),<sup>7</sup> we highlight here the particular example of access to cancer pain relief in selected settings.

In the context of wider palliative care development, an analysis of the global situation of palliative care,<sup>31</sup> led by Michael Wright, reveals striking variations both between and within world regions. The study categorizes hospice-palliative care development, country by country, throughout the world using a four-part typology. The four categories are:

1. no identified hospice-palliative care activity;
2. capacity building activity, but no service;
3. localized palliative care provision;
4. countries where palliative care activities are approaching integration with mainstream service providers.

Palliative care services were found in 115/234 countries. The total numbers of countries in each category were: no identified activity 78 (33 percent), capacity building 41 (18 percent), localized provision 80 (34 percent), and approaching integration 35 (15 percent).

This typology differentiates levels of palliative care development in both hemispheres and in rich and poor settings. In category four, hospice-palliative care services are characterized by: a countrywide critical mass of activists; a range of providers and service types; a broad awareness of palliative care on the part of both health professionals and local communities; a measure of integration of palliative care services with mainstream service providers; the availability of strong pain-relieving drugs; palliative care influence on policy; the development of recognized education centers; academic links with universities; the performance of research; and the existence of a national association. Category three countries are characterized by the development of a critical mass of activists in one or more locations, the establishment of a hospice-palliative care service, the growth of local support, the sourcing of funding, the availability of morphine, and the provision of training by hospice and palliative care organizations. In category two, there is evidence of a range of capacity building activities designed to create the organizational, workforce, and policy capacity for hospice-palliative care services to develop, albeit with no current services identified. Finally, in 78 countries there is no contemporary evidence of palliative care interest.

Although half of the world's countries have a palliative care service, development remains extremely patchy and seems to be driven more by local contingencies and the involvement of specific leaders and innovators, rather than on the basis of population need or public health principles. For example, in North America, both Canada and the USA are in category four (approaching integration), whereas in Greenland, no palliative care activity could be identified. In Latin America, the two southernmost countries, Argentina and Chile, fall into category

four. Costa Rica, however, stands alone in category four among the countries of Central America and the Caribbean. In Western Europe, with the exception of Portugal, Luxembourg, and a few small countries, such as Andorra, all countries are in category four. In Central and Eastern Europe, however, with the exception of Hungary, Poland, Romania, and Slovenia, all countries are in category three, localized provision. In Western Asia and the Middle East, only Israel is in category four, whilst in many countries throughout the region, no service could be identified. In Africa, only Uganda, Kenya, and South Africa have achieved a level of integration with wider health services. In 32 of the 48 African countries, no service could be identified. In the Asia Pacific region, a patchwork of initiatives was identified, but only a small number of countries is approaching integration with wider health services. In Oceania, only Australia and New Zealand have achieved such integration.

We now highlight these issues in more depth in three case studies: India,<sup>32</sup> a study led by Liz McDermott, the six countries in the Middle East,<sup>33</sup> led by Amanda Bingley and Africa,<sup>34</sup> led by Michael Wright.

## India

In the Indian example, a country in the localized provision category of development, we see a picture of mixed fortunes.

In India, it is estimated that one million new cases of cancer occur each year, with over 80 percent presenting at stage III and IV.<sup>35</sup> Two-thirds of patients with cancer are “incurable”<sup>36, 37, 38</sup> and approximately one million people are experiencing cancer pain every year.<sup>39</sup> It is difficult to assess the exact requirement for palliative care because of inadequate disease registration, cultural stigma, and communication problems.

The IOELC review conducted in 2005–2006 set out to assess the current state of palliative care in India, mapping the existence of services state by state and exploring the perspectives and experiences of those involved. One hundred and thirty-five hospice and palliative care services were identified in 16 states. These are usually concentrated in large cities, with the exception of the state of Kerala, where they are much more widespread. Non-government organizations, public and private hospitals, and hospices are the predominant sources of provision. There are 19 states or union territories in which no palliative care provision could be identified. Development of services is uneven, with greater provision evident in the south than the north.

The history of palliative care in India began in 1975 when the government initiated a National Cancer Control Programme. By 1984, this plan was modified to make pain relief one of the basic services to be delivered at primary healthcare level, although it has not been readily translated into extensive service provision.<sup>40</sup>

In 1986, Professor D'Souza opened the first Indian hospice, Shanti Avedna Ashram, in Mumbai, Maharashtra, central India.<sup>41</sup> Concurrently, pain clinics were established (at the Regional Cancer Centre, Trivandrum, Kerala and at Kidwai Memorial Institute of Oncology, Bangalore, Karnataka) and oral morphine was made available, free of charge, for the first time.<sup>35, 42, 43</sup>

From the 1990s onwards, there was a significant increase in the momentum of development of hospice and palliative care provision in India. This was demonstrated by an expansion in the number of services, as well as other key events and initiatives. The few services established were able to act as examples of the ways in which care could be offered to people at the end of their lives. Of significance was the establishment in 1993 of the Indian Association of Palliative Care (IAPC), during a workshop arranged with the guidance of WHO and the Government of India,<sup>44</sup> and in 1995 the IAPC set up a Palliative Care Drugs Committee and Educational Task Force.<sup>45</sup>

The mid to late 1990s saw a range of developmental activities. CanSupport was founded by Harmala Gupta in Delhi to provide the first free palliative care home care support service in north India. In Pune, Maharashtra, the Cipla Cancer Palliative Care Centre was established which, in consultation with Cancer Relief India, developed a new concept of a "living" palliative care center<sup>46</sup> with 50 beds arranged round a quadrangle with a children's playground in the middle. In addition, the Pain and Palliative Care Clinic was established at Medical College Hospital in Calicut, Kerala.

At the beginning of the 1990s, north Kerala did not have any palliative care facilities and there was only an outpatient pain clinic in Trivandrum, south Kerala. In 1993, a small group of doctors and social activists, all personally involved in the terminal care of cancer patients, organized an outpatient palliative care service at Calicut Medical College providing for both the physical and emotional needs of patients. It aimed to be free and accessible to poor patients in a context that was "adapted to the Indian scenario."<sup>37</sup>

In June 1996, a homecare service was set up with the aim of "delivering palliative care to the patients who are unable to reach the hospital, to empower patients to care for themselves and to empower the family to care for patients."<sup>47</sup> The homecare service was delivered by a doctor and some trained volunteers. In the first year of operation, the homecare team made 340 visits and concluded that home-based, volunteer-delivered palliative care may be the most suitable way to deliver palliative care to people in need in that area of Kerala.

The success of the home care program led to the Neighbourhood Network in Palliative Care (NNPC) initiative in 2001, which attempts to develop a sustainable community-led service capable of offering comprehensive long-term care (LTC) and palliative care (PC) to those in need.<sup>48</sup> In this program, volunteers from the local

community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals. The NNPC programs appear to have been very successful in the areas where they have been launched. In Malapuram, a poor district in Kerala with a population of four million, the coverage of LTC and PC rose to 70 percent in two years. There is an NNPC clinic roughly every 10 km which means patients should not have to travel more than 5 km. The concept took ten years to evolve and is now being subject to careful evaluation.

Finally, there are three government-funded centers which have been successful at providing and developing hospice and palliative care provision in India: Kidwai Memorial Institute of Oncology, Bangalore; Trivandrum Regional Cancer Centre, Kerala; and Tata Memorial Cancer Hospital, Mumbai. These centers run palliative care courses and raise awareness of palliative care in their area, as Dr Cherian Koshy of Trivandrum comments:

We have been able to train a sizeable number of doctors who have gone through the one month hands-on training, which equips them to stock morphine. And we also have frequent training programs, one day, two day, three day, short training programs. We have quite a large number of nurses who have been trained. And this message of palliative care I think has already become a movement in our state. And we even have medical students coming... and people are aware about this philosophy of palliative care.<sup>49</sup>

## The Middle East

In 2005, a study by the IOELC identified a total of 69 palliative care services across the six member countries of the Middle East Cancer Consortium (MECC).<sup>33</sup> The Palestinian Authority and Turkey were described as in the initial capacity building stage of palliative care development. Jordan and Egypt were identified as providing localized provision and Cyprus and Israel were considered to be approaching integration.

Home care services are the most common type of palliative care service provision in the region, although there is no home care in Egypt, Palestinian Authority, or Turkey. In Cyprus, two charities provide all the specialist services in the Greek Cypriot south and one provides some limited support in the Turkish Cypriot north.

In Israel, there is one major Non-Government Organization (NGO) that provides funding towards several services, educational and research activity, and public education programs. In the Palestinian Authority, one NGO offers psychosocial support for women with breast cancer at the end of life, as well as support for breast cancer survivors and other health-related services.

Of the 11 hospice inpatient palliative care units in the region, seven are freestanding (Cyprus, one; Egypt, two; and Israel, four). The remaining four units are dedicated specialist beds based within hospital oncology wards in Israel and Jordan. These kinds of specialist inpatient units are distinct from hospital-based consultation services offered at the end of life. In such situations, professionals who are aware of the principles of palliative medicine or who have completed some specialist training provide pain and symptom management. They are often constrained from developing full palliative care services because of limited resources, a lack of trained staff, and little support from colleagues. In 2005, this type of provision was the only service available in Turkey, although there were some motivated oncologists working to develop more comprehensive services in several major hospitals. In the Palestinian Authority and Egypt, this kind of service continues to be the main type of provision.

Opioids are reported to be available in all MECC countries. Cyprus, Egypt, Israel, Jordan, and Turkey make annual returns of data on opioid preparation and consumption, as sovereign states and members of the INCB. The Palestinian Authority is not an acceded party to the conventions of the INCB and therefore has no published figures for the consumption of narcotic drugs. A limited range of opioids is available for use in oncology units in the West Bank and Gaza Strip, although choice and availability of drugs cannot be guaranteed.<sup>50</sup>

The range of available drugs varies in different countries, but all MECC members report access and usage of common generic opioids used in palliative care, including codeine and generic morphine preparations. Healthcare professionals across the region note a general trend away from the use of morphine and an increase in use of more expensive proprietary opioids, in particular transdermal fentanyl. INCB data confirm anecdotal reports, from physicians and oncologists in the region, who observe widespread prescribing of fentanyl preparations, notably highest in Israel and Turkey, but widely used in Cyprus and Egypt. In Israel, physicians also note an increase in use of other opioid derivatives, such as hydrocodone and oxycodone.

All MECC member countries now have some form of government legislation for opioid availability and prescribing powers for physicians. Quantities permitted per prescription range from sufficient medication (of any appropriate strength) for three days up to ten days supply. In Israel, the maximum (and exception) at any one time is a 30-day supply. As part of opioid awareness and education, Israel, Cyprus, and Jordan routinely include pharmacists in their palliative care training courses. The increase in training opportunities in Israel and Cyprus has resulted in markedly less antagonism and phobia from healthcare professionals and consequently their patients. Opioid phobia, however, remains a considerable barrier to adequate opioid prescribing in Turkey and Jordan.

Education and training in palliative care is available internationally at postgraduate and fellowship level for all healthcare professionals in the MECC region who have the means to travel, or are supported through NGO or other charitable funding. Israel, with the most integrated palliative care services, is the only country in MECC that has some core training units in palliative care for medical students, and has also developed a national specialist postgraduate qualification in the subject. Cyprus, Israel, and Jordan have short units during core nursing training and Egypt has some palliative care training in development for core nursing education. International opportunities in palliative care education are a vital part of raising awareness and providing access to training courses for all MECC members – in the case of physicians in the Palestinian Authority and Egypt, such opportunities represent the only viable training option.

Despite a varied picture in terms of population patterns, healthcare systems, palliative care needs, and stages of palliative care service development, Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey share many of the major barriers to service development: lack of training, resources, problems with government legislation, and insecure funding. Cyprus and Israel have the most advanced development and Jordan and Egypt have some localized provision, albeit more developed in Jordan than Egypt. The Palestinian Authority and Turkey are capacity building, although the Palestinian Authority lacks any real resources for service development or pain and symptom management. In contrast, Turkey is experiencing increasing awareness of palliative care with Turkish cancer and pain specialists becoming active in palliative care service development.

## Africa

Several initiatives are underway to promote the development of hospice and palliative care in Africa. WHO is involved in a joint palliative care project for cancer and HIV/AIDS patients in the five countries of Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe.<sup>51</sup> The Diana, Princess of Wales Memorial Fund has supported palliative care initiatives in the nine countries of Ethiopia, Kenya, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe.<sup>52</sup> The Foundation for Hospices in sub-Saharan Africa,<sup>53</sup> now a part of the National Hospice and Palliative Care Organization in the USA,<sup>54</sup> has a growing program of twinning schemes. The Open Society Institute has a grant support program for southern Africa.<sup>55</sup> An evidence base for the African palliative care context is also beginning to emerge with analyses of models of service delivery<sup>56</sup> and an appraisal of the literature relating to services in sub-Saharan Africa.<sup>57</sup>

The history of hospice development in Africa stretches back to the late 1970s, when services first appeared in

Zimbabwe and in South Africa. Island Hospice was founded in Harare in May 1979 and had developed 17 regional branches by 1997.<sup>58</sup> In the late 1970s, hospice initiatives were also developing in South Africa – in Johannesburg, Port Elizabeth, Cape Town, and Durban. The visit of Cicely Saunders to South Africa in 1979 added impetus to these developments and within a year or two hospice organizations were operating in a variety of settings throughout the country. After the start made in these two countries, it was another decade before hospice and palliative care developments began to occur elsewhere in Africa: in Kenya and Swaziland (1990); Botswana, Tanzania, and Zambia (1992); Uganda (1993); Sierra Leone (1994); Morocco (1995); Congo-Brazzaville and Nigeria (1996); Malawi (1997); Egypt (2001), and the Gambia (2004).

The IOELC<sup>34</sup> review identified 136 hospice and palliative care organizations in 15 countries, an area with a population of 407 million people. The vast majority of these are nongovernment, charitable, and faith-based organizations. Over half (76) were found in South Africa, which has more such organizations than all of the other African countries combined (**Table 8.1**).

Although in South Africa there are 37 organizations with free-standing hospice inpatient facilities, 8/15 countries with hospice-palliative care in Africa have no such facility and, in general, there is an emphasis on the development of home care services. These are found in 14/15 countries and are provided by 111 of the 136 organizations identified. Forty-nine organizations have hospital-based services, found in 11/15 countries. Day care services and clinics are run by 87 organizations in 14/15 countries.

This limited development of hospice-palliative care organizations is also reflected in the low level of opioid use across the continent (**Figure 8.1**).<sup>59</sup> Yet, whilst a clear match exists between the country with the most reported defined daily doses of morphine and that with the most hospice and palliative care services (South Africa), it is difficult to explain why Namibia, the Central African Republic, and Tunisia report higher morphine use than other countries when the review could identify no hospice or palliative care services in those countries. Across Africa there are many reported problems of morphine availability and these are exacerbated by fears of using the drug, both on the part of practitioners and patients.

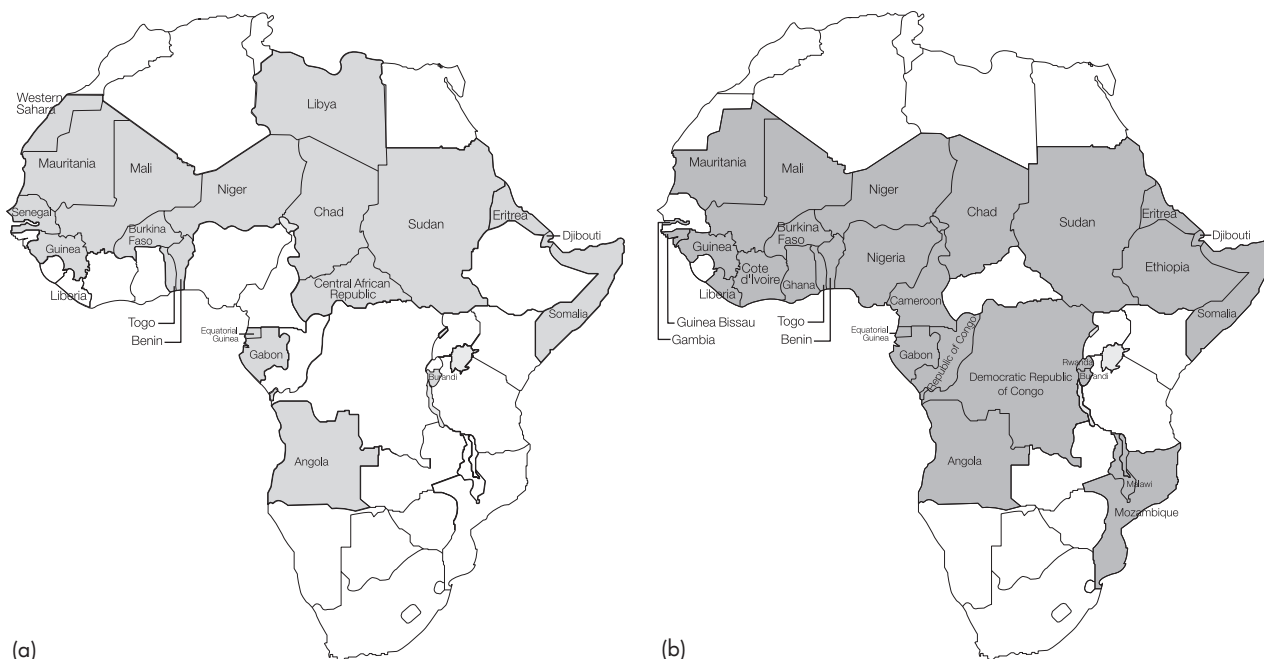
Nevertheless, there are some examples of outstanding success in tackling the problem of morphine availability. In Uganda, morphine for cancer and HIV/AIDS patients is provided free of charge by the government and, in a groundbreaking innovation of March 2004, a Statutory Instrument<sup>60</sup> was signed by the Minister of Health authorizing palliative care nurses and clinical officers to prescribe morphine.

## CONCLUSIONS

The problems we have described in this chapter are not those of poverty and underdevelopment alone, though such factors play their part. Many countries still have hugely inadequate supplies of appropriate pain medication, even though this can be made available at low cost. Some governments put in place draconian measures to limit the manufacture, sale, transportation, storage, and

**Table 8.1** Hospice and palliative care: organizational provision in Africa (15 countries).

Country	No. of organizations	No. of known branches	Organizations making inpatient provision		Organizations making outpatient provision	
			Hospice	Hospital	Home care	Day care/clinic
Botswana	3	0	0	1	3	3
Congo	1	0	0	1	1	0
Egypt	3	0	2	1	1	1
Kenya	8	3	0	6	8	6
Malawi	5	0	0	4	2	3
Morocco	1	0	0	1	0	1
Nigeria	2	0	0	1	1	1
Sierra Leone	1	0	1	0	1	1
South Africa	76	42	37	19	61	49
Swaziland	4	0	1	0	3	2
Tanzania	4	0	0	3	3	3
The Gambia	1	0	0	0	1	1
Uganda	8	124	2	6	7	6
Zambia	6	0	6	0	6	6
Zimbabwe	13	6	2	6	13	4
Total	136	175	51	49	111	87



**Figure 8.1** African countries with (a) no reported morphine use and (b) those with no known palliative care.

prescription of strong opioid drugs. Too often the balance between “regulation” and “availability” is tipped in favor of the regulators, to the extent that simple pain-relieving measures are largely unavailable. The problem is compounded by clinicians made nervous about prescribing strong painkillers for risk of social opprobrium, or even prosecution. The world of cancer pain and palliative care services is divided between the “haves” with access to a range of appropriate medications and the knowledge and will to use them – whilst the “have nots” are denied even simple formulations. The underdevelopment of cancer pain and palliative care services globally does a disservice to those who could benefit from improved provision and is frankly unjust. Good care for cancer patients, including the relief of pain at the end of life and the opportunity for a dignified death, should be regarded as basic human rights to which everyone should have access when the time comes.

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