Original Article

Hospice and Palliative Care Development in India: A Multimethod Review of Services and Experiences

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Abstract
Palliative care has been developing in India since the mid-1980s, but there is a dearth of evidence about service provision on which to base national policy and practice. The aim of this study was to assess the current state of palliative care in India, mapping the existence of services state by state, and documenting the perspectives and experiences of those involved. A multimethod review was used, which included synthesis of evidence from published and grey literature, ethnographic field visits, qualitative interviews with 87 individuals from 12 states, and collation of existing public health data. The review identified 138 hospice and palliative care services in 16 states and union territories. These are mostly concentrated in large cities, with the exception of Kerala, where they are much more widespread. Nongovernmental organizations, public and private hospitals, and hospices are the predominant sources of provision. We were unable to identify palliative care services in 19 states/union territories. Development of services is uneven, with greater provision evident in the south than the north, but for the majority of states, coverage is poor. Barriers to the development of palliative care include: poverty, population density, geography, opioid availability, workforce development, and limited national palliative care policy. Successful models exist for the development of affordable, sustainable community-based palliative care services. These have arisen from adapting Western models of hospice and palliative care for implementation in the Indian cultural context. Further work is required to ensure that the growing interest in hospice and palliative care in India is used to increase the momentum of progress.

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Key Words
Palliative care, hospice, India, development

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Introduction

India is a challenging country for those involved in developing palliative care. The population is estimated to be over one billion, which is approximately one-sixth of the world’s population. In 2000, the World Bank Development report noted that 89% of the population lives on less than US$2 a day and 53% on less than US$1 a day.1 The impact of globalization has generated substantial gains in economic investment and yield, but India faces serious, enduring problems of widespread poverty and overpopulation. Vast numbers of people live in rural impoverishment, with poor access to transport and communications, and low indices of nutrition and health.

It is difficult to assess the exact requirement for palliative care because of inadequate disease registration, communication problems, and the cultural stigma attached to cancer and HIV/AIDS. Cultural attitudes and low literacy rates in many states of India foster an ignorance and fear of cancer, HIV/AIDS, and other life-threatening diseases. It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV.2 The commonest cancer diagnoses for men are head and neck (especially tongue and mouth), stomach, lung, and esophagus. For women, the most prevalent cancers are cervix, breast, head and neck, esophagus, and ovary.3–4 Experience from cancer centers suggests that two-thirds of patients with cancer are incurable at presentation and need palliative care5–7 and approximately one million people are experiencing cancer pain every year.8

India is one of the few countries that initiated HIV-prevention activities in the very early stages of the epidemic, and the country has maintained its commitment to prevention efforts, including free antiretroviral treatment in government hospitals.9 India’s socioeconomic status, traditional social norms, cultural beliefs on sex and sexuality, large-scale migration, and a huge population of marginalized people make it extremely vulnerable to the AIDS epidemic. However, HIV/AIDS patients have received very little attention in terms of palliative care.9

The difficulties of developing hospice and palliative care services in such conditions should not be underestimated. The combination of huge numbers of people living in deprived conditions, a lack of resources and national palliative care policy, and the marginalization of palliative care within the medical establishment would discourage even the most committed palliative care professional. Despite these problems, through the tireless work of many dedicated people there has been an improvement in the extent of palliative care service provision in India, albeit slow and uneven. In a country as vast and diverse as India, it should not be surprising that one state can develop a World Health Organization (WHO) designated demonstration project on community-led palliative care services while simultaneously other states/union territories are without any palliative care facilities.

It is in this context of dichotomous developments in Indian palliative care that this multi-method review of developments sought to provide national evidence, which until now has been unavailable to practitioners, policymakers, and state and government officials.

Study Aims

Palliative care provision in India has been developing, but progress has been slow and uneven. This review aimed to establish a thorough evidence base on palliative care services currently operating in India, and to identify strengths and weaknesses in the state of development across the subcontinent. This level of detailed evidence will aid informed debate and improve policy-making among state and national governments on the issues facing end-of-life care in India. A review may also provide stimulus to new research capacity building.

Methods

The study was conducted as part of the global development program of the International Observatory on End of Life Care at Lancaster University, UK.10,11 Within the program, we are assembling a systematic overview of palliative care development across the globe, with a particular focus on low and medium resource countries. A review methodology has been developed,12,13 which analyzes the
current state of hospice and palliative care at the national level against key parameters. Resulting country reports are then published for open access on the International Observatory on End of Life Care web site (http://www.eolc-observatory.net/). This review methodology consists of a number of components. First, we collect and analyze relevant demographic, epidemiological, and health system data obtained from governmental, public health, and nongovernmental organization (NGO) sources, both within and outside the country. Second, we undertake nonanonymized, in-depth qualitative interviews with key in-country experts and palliative care activists, both by telephone and face to face. The aim of these narratives is to reveal both the stories of how and why individuals become involved in hospice and palliative care developments, and also the perceived challenges, opportunities and envisaged plans for the future. Third, we conduct a systematic search and analysis of publicly available hospice, palliative care and associated material, including grey literature (annual reports, service statistics, technical papers), in addition to information from web-based sources and electronic communication. The search for relevant material includes site visits, ethnographic fieldwork and the formation of a countrywide network of collaborating colleagues to assist data compilation and validate findings.

The data generated from this multimethod approach are analyzed through an established format that results in the production of individual country reports. Each country report is produced against an agreed template, which includes a homepage containing a map and geopolitical information. Country reports document details of current palliative care services, including how these are funded and reimbursed; estimates regarding the workforce capacity and coverage; and details of educational programs. Opioid availability data are presented along with information on the public health context, population, epidemiology, health care system, and political economy. Significant ethical issues in the delivery of hospice and palliative care are recorded. The narrative history of hospice and palliative care is presented alongside case studies of individual “success stories” and oral histories of key individuals and activists.

The findings are validated through an established mechanism. Draft country reports are disseminated to key experts in-country for inspection and authentication. In this phase, factual errors are removed, omissions identified, and the text revised. When this process is completed, the finished report is published on the World Wide Web within the global development section of the International Observatory on End of Life Care web site.14

The data collected through this method for the review of palliative care development in India involved 87 interviews in 12 states, as well as a nine-month field visit to both the main centers and other, more peripheral, services. The data were collected over a two-year period from 2004 to 2006 and include material obtained at the Indian Association of Palliative Care conferences in 2004, 2005, and 2006. During this time, a network of collaborating colleagues, particularly members of the Indian Association of Palliative Care, was established across the country.

Results

Historical Development of Services and Current Provision

The concept of palliative care is relatively new to India, having been introduced only in the mid-1980s. Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries. In 1975, the Government of India initiated a National Cancer Control Programme.15 By 1984, this plan was modified to make pain relief one of the basic services to be delivered at the primary health care level. Unfortunately, this policy was not translated into extensive service provision.9 The hospice and palliative care movement in India started tentatively in the mid-1980s and has slowly increased over the last two decades. There is still no national palliative care policy.

Our review identified over 138 organizations currently providing hospice and palliative care services in 16 states or union territories (Table 1). These services are usually concentrated in large cities and regional cancer centers, with the exception of Kerala, where
services are more widespread. NGOs, public and private hospitals, and hospices are the predominant sources of provision. Development of services is uneven, with more services found in the south than the north. In the majority of states, coverage is poor. We were unable to identify palliative care provision in 19 states or union territories.

Hospice and palliative care services are found in settings that include: regional cancer centers; free-standing hospices; government and private hospitals; outreach clinics; and day and home care services run from other designated buildings (e.g., health centers, schools). The majority of these services can be characterized as inpatient provision (in hospices or hospitals); outpatient clinics (in hospitals and other settings); and home care services (run by hospitals, hospices or volunteer networks). The distribution by state/union territory of the different hospice and palliative care services is illustrated in Table 1.

### Table 1: Palliative Care Provision in India by State/Union Territory

<table>
<thead>
<tr>
<th>State/Union Territory</th>
<th>Services; n</th>
<th>Ratio of Service to Population 1:000s</th>
<th>Inpatient Services; n</th>
<th>Outpatient Services; n</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hospice</td>
<td>Hospital</td>
</tr>
<tr>
<td>Andhra Pradesh</td>
<td>3</td>
<td>25403</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Assam</td>
<td>5</td>
<td>5331</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>3/4</td>
<td>225</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Goa</td>
<td>1</td>
<td>1347</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>3</td>
<td>16890</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Karnataka</td>
<td>5</td>
<td>10570</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Kerala (by district)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alappuzha</td>
<td>2</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Calicut</td>
<td>15</td>
<td></td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Ernakulam</td>
<td>5</td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Idukki</td>
<td>3</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Kannur</td>
<td>4</td>
<td></td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Kollam</td>
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<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Kotayam</td>
<td>3</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Malappuram</td>
<td>20</td>
<td></td>
<td></td>
<td>20</td>
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<tr>
<td>Palakad</td>
<td>5</td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Thrissur</td>
<td>5</td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Trivandrum</td>
<td>9</td>
<td></td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Wynad</td>
<td>11</td>
<td></td>
<td></td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>83</td>
<td>384</td>
<td>9</td>
<td>6</td>
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<tr>
<td>Madhya Pradesh</td>
<td>6</td>
<td>10064</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Maharashtra</td>
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<td>19376</td>
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<td>1</td>
</tr>
<tr>
<td>New Delhi</td>
<td>3</td>
<td>4617</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Orissa</td>
<td>1</td>
<td>36805</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Punjab</td>
<td>1</td>
<td>24358</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>5</td>
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<td>2</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>12</td>
<td>5290</td>
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<td>5</td>
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<td>Uttar Pradesh</td>
<td>1</td>
<td>166198</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>West Bengal</td>
<td>1</td>
<td>80176</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>139</td>
<td>24</td>
<td>22</td>
<td>89</td>
</tr>
</tbody>
</table>

Ratio 1:000s population based on India 2001 Census (http://www.censusindia.net/).

States/union territories in India without identified palliative care provision: Andaman and Nicobar Islands; Arunachal Pradesh; Bihar; Chhattisgarh; Dadar and Nagar Haveli; Daman and Diu; Haryana; Himachal Pradesh; Jammu and Kashmir; Jharkhand; Lakshadweep; Manipur; Meghalaya; Mizoram; Nagaland; Puducherry; Sikkim; Tripura; Uttarakhand.

Patient Statistics. Statistics of the numbers of patients treated by hospice and palliative care services are not collected at a national or state level in India. There are no available national demographic data about which patients are accessing services or how patients are referred to services. Individual services do suggest that referral comes from both formal mechanisms, for example, through attendance at an outpatient clinic, and word of mouth where patient relatives request the service, or patients self-refer. Most hospices and palliative care services do keep records of patient activity, albeit often using different parameters.
Reimbursement and Funding for Services. In India, medical insurance does not play a significant role in hospice and palliative care provision. Services are funded in a range of ways including: central government; state government; NGOs; indigenous-fund raising; private companies; medical and pharmaceutical companies; private individuals and international donations. Many services rely on buildings provided by government or private hospitals but then have to generate their own funds to secure food, drugs, medical supplies, equipment, and some salaries. As a consequence, funding is, in the main, a continual source of concern and is often identified by service providers as a limitation upon service expansion.

Education and Training. Palliative care education and training in the subcontinent is provided at different levels by numerous organizations that include: medical colleges; individual hospitals and hospices; NGOs; international organizations such as the WHO, the Oxford International Centre/WHO Collaborating Centre; and overseas universities. However, training and education facilities are recognized to be inadequate for the country’s requirements. Unfortunately, there is only one approved training program through an Indian university (at Amrita, Kerala, South India) and there are approximately four medical colleges in the country that have some palliative care undergraduate training. The Indian Medical Council has yet to press for national palliative care training and there are insufficient qualified specialists within the country to provide training.

Opioid Availability

It is estimated that less than 3% of India’s cancer patients have access to adequate pain relief, and many states in India have no medical facilities that dispense morphine. Of the 16 states/territories with palliative care services, 14 reported prescribing morphine. However, there are immense difficulties regarding morphine availability. The licensing of morphine for medical purposes is governed by the state rather than by the central government. Government regulations are stringent, but an individual state/territory can adopt simplified narcotics regulations, which make it easier to purchase, store, and use morphine. There are 10 states/territories that have adopted these simplified regulations, but availability remains limited (Fig. 1).

There has been a sustained initiative to improve availability of and access to opioid analgesics through a WHO project. This is a partnership between the Pain and Policy Studies Group/WHO Collaborating Center at the University of Wisconsin Comprehensive Cancer Center, The Pain and Palliative Care Society (PPCS) (Calicut, Kerala), the Indian Association of Palliative Care, agencies of the Central Government of India, and several state government ministries of health. The collaboration has developed guidelines for obtaining morphine and held workshops on opioid availability with health care professionals and state officials across India.

There has been some success in improving access to opioids. The PPCS has been designated a WHO Demonstration Project providing national expertise and leadership in opioid availability, especially in the use and control of morphine. There continues to be a workshop program, which aims to ensure the national adoption and implementation of the simplified narcotic regulations across states and union territories. In addition, there are attempts to provide education for health professionals so that there is a body of expertise and training in the proper use of opioids.

Despite some success at improving the availability of morphine, progress is slow and many palliative care services in India have great difficulty obtaining a continuous supply of opioids, which can be frustrating for palliative care practitioners. The International Narcotics Control Board has been unable to regularly record complete data on the consumption of opioids in India. They have published the following figures for the consumption of narcotic drugs in India for 2004: opium 251 kg; pethidine 136 kg. In 2003, consumption figures were published for: pholcodine 176 kg; dextropropoxyphene 78,931 kg; and diphenoxylate 3,771 kg, in addition to codeine 15,346 kg and morphine 196 kg (both based on 2001 statistics because there were no figures available for 2003). Tamil Nadu, South India is one of the states that has adopted the simplified narcotics regulations; however, Dr. Mallika Tiruvadan, based at the Lakshmi Pain and Palliative Care...
Clinic, explains that this does not equate to a continuous supply of morphine:

I don’t have a supply at all. In almost the whole of Tamil Nadu, there is just the Regional Cancer Institute in Chennai which has the WHO stock of oral morphine, and only the immediate-release tablets, the 10 mg and the 60 mg... There were some dealers, just one or two dealers, a year or two ago, but they’ve all shut because they have all complained about constant harassment with going and renewing the licenses, obtaining the license. So they just don’t want to have anything to do with morphine. Now the morphine is being supplied by one or two pharmaceutical companies and it is also given away to one or two of the major hospitals. Now the thing is it’s sometimes available, sometimes it’s not.”
Opioid accessibility is a constant problem for the providers of hospice and palliative care in India. Our review identified a range of barriers to morphine availability, including:

- Stringent central government legislation
- State government reluctance to implement/ignorance regarding simplified narcotics regulations
- Difficulties with some state bureaucracy
- Fears about morphine addiction among state officials, health professionals, patients and their families
- Pharmaceutical companies unwilling to produce morphine
- Products prohibitively expensive
- Few dispensing services
- Health professionals’ lack of experience of prescribing morphine
- Fear of side effects in patients
- Little training/education about morphine provided to health professionals and the general public

Characterizing Development

The challenges to developing palliative care in India are immense. In addition to the problems of opioid accessibility, there is no national palliative care policy, medical and nursing education facilities are recognized to be inadequate for the country’s requirements, and services have to provide for high-density populations across huge geographical areas, with the majority of people living in impoverished circumstances. In response to these circumstances, palliative care development in India is characterized by an increasing number of home care services, which are able to reach large numbers of people. This home-based provision relies on the strength of family support and the enthusiasm of volunteers.

Our review identified 88 home care programs in operation across the subcontinent (Table 2). These are specific home care programs rather than services that provide occasional home visits. There are 63 home care services organized in the southern state of Kerala, in which a community participatory model of palliative care has been developed with enormous success. Home care services in India may be found operating from hospices, hospitals, health centers, and other premises. They are provided by a range of professionals such as doctors, nurses, and social workers, as well as by volunteers.

A notable characteristic of the home care programs developing in India is the willingness of palliative care activists, professionals, and volunteers to adapt Western models of hospice and palliative care to the differing local cultural contexts. In his discussion about the challenges of providing palliative care in India, Dr. M.R. Rajagopal, a founder of the PPCS, Kerala, elaborates on why this reinvention is critical to the successful service delivery:

Our suffering people need a system of palliative care delivery that is suited to our social and cultural milieu. It has to be inexpensive; we cannot possibly have enough expensive inpatient facilities for a million people. We can learn from the hospice system of the West, without duplicating it in its entirety. We have a strong point in our favour and that is the family structure in India. People generally prefer to live and die at home. If we have a system of delivery of palliative care based on treatment at home, with the relatives being empowered in the care of the patient, it has a definite chance of succeeding.

The development of palliative care home-based services, in both rural and urban settings, may go some way to address the problem of delivering low-cost end-of-life care to the population of this vast subcontinent. The review identified three states where palliative care home care services have been extensively and successfully developed (Kerala, New Delhi, Assam). We comment in more detail on these services in the following sections.

### Table 2

<table>
<thead>
<tr>
<th>State/Union Territory</th>
<th>No. of Organizations Providing Home Care Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assam</td>
<td>4</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>1</td>
</tr>
<tr>
<td>Karnataka</td>
<td>2</td>
</tr>
<tr>
<td>Kerala</td>
<td>63</td>
</tr>
<tr>
<td>Madhya Pradesh</td>
<td>1</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>4</td>
</tr>
<tr>
<td>New Delhi</td>
<td>2</td>
</tr>
<tr>
<td>Orissa</td>
<td>1</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>6</td>
</tr>
<tr>
<td>West Bengal</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>88</td>
</tr>
</tbody>
</table>
Kerala. At the beginning of the 1990s, north Kerala did not have palliative care facilities, and the single outpatient pain clinic was located at the Regional Cancer Centre 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 in northern Kerala. The clinic aimed to be free and accessible to poor patients and provide for both the physical and emotional needs of patients. The founders argued that the Indian experience of the previous decade illustrated that “the Western hospice system in its entirety is not practical in India. For cultural, economic and social reasons, India needs a system adapted to the Indian scenario.”

It was with this aim in mind that the outpatient service was founded.

The clinic opened with a part-time doctor and two volunteers. The first three years were a pilot and intended to “identify the problem areas, to modify the system and to evolve a model of palliative care suitable for the region.” An NGO, the PPCS, was formed and, in June 1996, the home care service was established with the aim of delivering palliative care to those patients unable to reach the hospital, and empowering patients and families to provide care. In the first year of operation, the home care team (a single doctor and a handful of trained volunteers) made 340 visits, and concluded that home-based, volunteer-delivered palliative care may be the most suitable way to meet patient needs in Kerala.

The success of the home care program led to the Neighbourhood Network in Palliative Care (NNPC) initiative in 2001. This is a joint venture with four NGOs and eight palliative care centers that attempts to develop a sustainable “community-led” service capable of offering comprehensive long-term care and palliative care to those in need. 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. Essentially, the NNPC aims to empower local communities to look after the chronically ill and dying patients in the community. NNPC programs have been remarkably successful in all the places where they have been launched. In Malappurum, a poor district in Kerala with a population of four million, where the program was first “ground tested,” the coverage of long-term care and palliative care rose to 70% of those in need in two years. There is now an NNPC clinic roughly every 10 km, which means patients can be easily accessed by home care teams based in the community.

The phenomenal success of this model of care has resulted in a growing network of over 63 palliative care clinics across Kerala, providing care free of charge to patients in need. In an interview in January 2005, Dr. Suresh Kumar reflected on 10 years of palliative care development in Kerala:

What has been happening over the last years—I think that the definite trend as far as northern Kerala is concerned—is palliative care moving out from the institution into the community, and this has been happening much faster than even some of us who are part of it expected. And from ’93 when the first palliative care clinic was started in Calicut, it was a very much institution-based, doctor/patient model. We had a few volunteers but they were doing odd jobs, you know, odd nursing jobs after training, and the whole team was centered around the doctor and there was some support from the community, financial, like some of the donations. Now we have reached the stage where most of the care is delivered in the community and the doctor in many palliative care units in northern Kerala is somebody who looks after or takes care of the physical problems, and most of the other issues like social support, the spiritual issues, other emotional problems are taken care of by the volunteers. Most of the units now are run by the local groups and they employ the doctor, that’s against the earlier clinics initiated by doctors and the volunteers and other people acting under him.

The NNPC is designated a WHO Demonstration Project for providing cost-effective community-based home care for late stage cancer patients, and national expertise and leadership in opioid availability, especially in the use and control of morphine.
New Delhi. A different model of home care has been developed in Delhi, North India. CanSupport started in 1997, the first palliative home care support service in north India. Founded by Harmala Gupta, the organization provides free home-based palliative care, day care, and counseling services, including bereavement support, for cancer patients and their families. CanSupport has four trained home care teams, each consisting of doctors, nurses, and counselors trained in palliative care. They visit the homes of approximately 80–85 patients with advanced cancer every week. Family members are trained in simple nursing tasks so they can keep the patient comfortable until the next home visit. Their patients are referred by the pain and palliative care clinic at the Institute Rotary Cancer Hospital, part of the All India Institute of Medical Sciences, and doctors at other cancer institutions.

In addition to the home care program, CanSupport has recently started a day care service for people with cancer and their families. In the following extract, Harmala Gupta speaks about what palliative care means for the CanSupport home care teams:

Yes, just an enormous problem, any area you touch there is a problem, which is why we have as you suggest gone beyond the traditional palliative care support and provided dry rations, dried food rations to people, sometimes help with transportation, we provide them with all kinds of medical aids. Really I think we also perform a much-needed social function, because families tell us that even their relatives have stopped visiting them. We realize there is so much ignorance around cancer a number of people believe it is contagious and they stop visiting, children are kept away from the person who is sick because there is this odd fear that perhaps a child is more vulnerable and they may catch it.

CanSupport is a different form of home-based service to the Kerala-based model. Harmala Gupta has raised criticisms regarding the suitability of community-based palliative care delivery. She questions whether quality palliative care can be provided by volunteer-led teams, and has generated a debate, within India and internationally, regarding community participation in palliative care.

Assam. The Guwahati Pain & Palliative Care Society (GPPCS) in Assam, northeast India, is the only organized palliative care service in the seven northeastern states. A registered NGO, it was the first service in Northeast India providing palliative care to people with advanced cancer. Its members, including three doctors, two nurses, voluntary nurses, 30 volunteers, and an office assistant, now run the GPPCS. It started initially with a weekly outpatient clinic providing free care, and established a home care service in June 2001. The service was able to expand successfully by using trained volunteers. GPPCS now has established link centers in three towns in Assam (Rangia, Digboi, and Hojai).

The GPPCS is a good example of the way home-based palliative care services have developed in response to the problem of delivering services to a large, widely dispersed, and impoverished population, and adapted to the cultural conditions of the state or province. GPPCS founders recognize that delivering care across a large geographical area with limited resources can be achieved through a volunteer-based model. Dr Kabin德拉 Bhagabati states:

Local volunteers come onto training courses, so we try to take volunteers from different places so they can do something to the persons in their locality and they can at least look after the patients and report to us and they can at least see that the patients—when they are taking their medicines.

Although the GPPCS service draws upon the NNPC model of a volunteer, community-led palliative home care service, Assam is a very different state to Kerala. The population is culturally and religiously diverse, with a large number of tribes. Dr. Dinesh Goswami argues that because of the cultural context of Assam, recruiting volunteers may need different strategies to those used in Kerala. He explains how volunteers are recruited:

…the scenario is not like the one in Kerala here: we started working, like going to offices then going to schools/colleges and taking a few minutes time and we used to talk about our activities and give our leaflets and other things, so they can have an idea about what we are doing and what our mission is, and after that they react to it and
then we invite them to come to the clinic and have some more knowledge, and that way we involve people from the community for the training.41

Conclusions

This review of hospice and palliative care development in India uncovers a contradictory progress. On the one hand, the barriers to improving hospice and palliative care provision in India are multiple, complex, and entrenched; on the other, these challenges have been tackled over the last two decades, and although not always overcome, successful indigenous approaches are gradually emerging.

Indian palliative care development at its most successful has innovated and produced services such as the NNPC, which provides an exemplar model of community-based palliative care for other low-resource countries worldwide. The service models discussed here are evidence of the way in which the Western concept of hospice and palliative care is being reshaped to suit the diverse economic, social, and cultural conditions of the subcontinent. The innovation, enthusiasm, and commitment of volunteers, families, activists, and palliative care practitioners are clearly the driving force of Indian palliative care. Collaborations between the Government of India, Indian Association of Palliative Care and WHO provide further optimism regarding future development. Our review found additional positive characteristics, such as the growing public and medical acceptance of palliative care, the increasing number of volunteers, and the ongoing partnership with international support agencies such as the International Association for Hospice & Palliative Care.

Despite these successes, palliative care provision is still severely underdeveloped, with 19 states/union territories without services and most states, with the exception of Kerala, having limited palliative care provision concentrated in large cities. Opioid availability and continuing opiophobia within the medical profession remain major difficulties. At a national level, palliative care policy is minimal. In conjunction with insufficient funding for services and the absence of a state-sponsored social security system or effective medical insurance scheme, this makes it very difficult to develop palliative care provision further. Health professionals active in developing palliative care in India have recognized the need to press the Indian Government to design and implement a national palliative care policy if they are to bring about substantial change.9,42 They argue that this must coexist with strategies to increase the public awareness of palliative care; include palliative care in medical and nursing curricula; and improve drug availability and expertise.

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