



POLICY BRIEF DOCUMENT: PALLIATIVE CARE FOR
OLDER PERSONS IN INDIA



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PREFACE

The purpose of this report

This report is intended to inform the deliberations of those engaged in developing policies on palliative care for the older persons as well as other stakeholders with an interest in such policy decisions. It summarizes the best available evidence regarding the design and implementation of policies on how to advance palliative care in India's [mainstream] health system for the older persons.

The purpose of the report is not to prescribe or proscribe specific options or implementation strategies. Instead, the report allows stakeholders to consider the available evidence about the likely impacts of the different options systematically and transparently.

How this report is structured

The report is presented in two parts. The first is a section on Key Messages which outlines each section. This may be particularly useful to those who do not have enough time to read the full brief. The second part contains the full report: this details the problem, the available evidence used to address the problem, and the approaches that were used during the preparation of the brief.

How this report was prepared

This report brings together both global and local evidence to inform deliberations about advancing the integration of palliative care services for the older persons in the health system. Relevant evidence was searched describing the problem, the impacts of options for addressing the problem, barriers to implementing those options, and implementation strategies to address those barriers. The search for evidence focused on relevant systematic reviews regarding the effects of policy options and implementation strategies. Information from other relevant studies was included when systematic reviews were unavailable or insufficient. Other documents, such as government reports and unpublished literature, were also used.

Why have systematic reviews been focused

Systematic reviews of research evidence are a more appropriate source of research evidence for decision making than the latest or most heavily-publicized research studies [1,2]. The term 'systematic review' refers to a review of the research literature that has an explicit question, an explicit description of the search strategy, an explicit statement about which types of research studies it included and excluded, a critical examination of the quality of the studies included in the review, and a critical and transparent process for interpreting the findings of the studies included in the review.

Systematic reviews have several advantages [1]: firstly, they reduce the risk of bias in selecting and interpreting the results of studies. Secondly, they reduce the risk of being misled by the play of chance when identifying studies for inclusion, or the risk of focusing on a limited subset of relevant evidence. Thirdly, systematic reviews provide a critical appraisal of the available research and place individual studies or subgroups of studies in the context of all the relevant evidence. Finally, they allow others to

appraise critically the judgements made in selecting studies and the collection, analysis, and interpretation of the results.

Uncertainty does not imply indecisiveness or inaction

Most of the systematic reviews included in this brief concluded that there was “insufficient evidence”. Uncertainty about the potential impacts of policy decisions does not mean that decisions and actions cannot or should not be taken. However, it does suggest the need for carefully planned monitoring and evaluation when policies are implemented [3].

Limitations of this report

This report is based largely on existing systematic reviews, as well as local and global single studies. Summarizing evidence requires judgements about what evidence to include, the quality of the evidence, how to interpret it, and how to report it. This brief is thus based on the judgements made by the review authors and judgements made by me, but I have attempted to be as transparent as possible about these processes.

Key message

This policy brief contributes to the evidence base of policy development for scaling up palliative care services for older persons who need them, across India. Scaling up publicly provided palliative care services will help India meet several Goals and Targets of the 2030 Agenda for Sustainable Development. The Ministry of Health & Family Welfare, Government of India has identified many stakeholders with relevant expertise in the field of palliative care and care for older persons (including policymakers, researchers, members of civil society, and palliative care practitioners/ geriatricians). The information and viewpoints they provided helped to define the problem, identify potential policy solutions, as well as implementation considerations. All these concerns are addressed in this report. This section gives a brief overview of it.

The problem:

High burden, but approximate estimations

In high-income countries, 69%-82% of those who die need palliative care [1]. In absence of such data for India, such derivations are mostly indirect. Home to one-sixth of the World's population, India has a huge burden of suffering from non-communicable diseases (NCDs) and life-limiting illnesses.

Cardiovascular diseases (coronary heart disease, stroke, and hypertension) contribute to 45% of all non-communicable disease (NCD) deaths followed by chronic respiratory disease (22 %), cancers (12 %) and diabetes (3%) in India [2]. Majority of cancers will need palliative care; however, patients with cardiovascular disease, liver and renal pathology, and neurological and respiratory diseases, and AIDS may also require such care. According to Population Census 2011 there are nearly 104 million older persons (aged 60 years or above) in India; 53 million females and 51 million males. The toll of NCDs (measured by years of life lost) on people ages 60 and older in low- and middle-income countries is much greater than for people in high-income countries [4]. Advancing age is again a high risk factor for cancer, with persons over 65 accounting for 60% of newly diagnosed malignancies and 70% of all cancer deaths [5]. Given that an additional two family or voluntary caregivers per patient may also need support, it is therefore likely that the total number of people requiring help is much more. There are four major palliative care delivery models in India presently: ambulatory clinics, home-based programs, inpatient palliative care units, and inpatient consultation services [6]. But, there are gaps in service provision due to various reasons (discussed later) which can be summarized to inefficient health care plans, low healthcare utilization and low spending in terms of GDP (gross domestic product) per capita in health care [7]. This has resulted in less than 1% of India's population having access to pain relief and palliative care [8].

The Policy Environment

Indian constitution

Access to palliative care is now recognised as a fundamental human right. The framers of the Indian Constitution were influenced by the concept of human rights and guaranteed Indian citizens most of human rights contained in the Universal Declaration of Human Rights. They incorporated civil and political rights into Part III of Indian Constitution, and health, education, and cultural rights into Part IV

as “Directive Principles of States Policy”. The inclusion of important provisions of Universal Declaration of Human Rights in the Constitution of India has given them supremacy over all other statutory provisions. Palliative care is fundamental to health and human dignity and is a basic human right. Palliative care is highly effective in managing pain and physical symptoms and can improve adherence to medications [9]. It was in the early 1990s that an appeal was made, both in India and globally, for access to palliative care to be treated as a human rights issue. Over the past few years, India has witnessed robust advocacy efforts which push for the consideration of palliative care and pain management as a human right. Central to this is India’s Narcotic Drugs and Psychotropic Substances (NDPS) Act, 1985: its genesis, its critique, and the amendments aimed at enhancing access to the NDPS for medical care and research. On the Occasion of World Cancer Day 2012, Pallium India, International Association for Hospice and Palliative Care (IAHPC), Pain & Policy Studies Group, University of Wisconsin / WHO Collaborating Center for Pain Policy and Palliative Care (PPSG) declared the importance of morphine availability for relief from pain [10]. Catholic Health Association of India (CHAI) has also signed a MoU with Pallium India in September 2017 [11].

Multi-lateral global

There have been many notable international events where palliative care and access to opioid medications have been discussed and successfully adopted in policies for mainstream health care, like: 2017 World Health Assembly (WHA) cancer resolution, 2014 WHA 67.19 Resolution, UNGASS “Outcome Document” and UNGA Resolution on the World Drug Problem in 2016, the 2030 Agenda for Sustainable Development and its 17 Sustainable Development Goals, 9th Session of The Open-Ended Working Group on Ageing (will be held in July 2018), CESCR General Comment No. 14, announcements from the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Human Rights Council, and religions together for Palliative Care for older people meeting.

Palliative Care: National Policies / Laws

During 2012, the Ministry of Health and Family Welfare developed a National Palliative Care Strategy. Following the creation of the National Strategy, Pallium India, with support from WHO (India), organized a working group meeting at Trivandrum in January 2013 to develop a framework for implementation of the palliative care strategy. The draft framework created by the working group was submitted to WHO (India) for operational analysis, as decided at the working group meeting. Palliative care was included in the National Health Policy 2017 [12].

Palliative Care: State Policies / Rules

India has 28 states and 7 Union Territories. Health care is the responsibility of the State Government, each state creating its own policy. On April 15, 2008, Kerala announced a State Palliative Care Policy, integrating palliative care into the government’s healthcare system. Kerala State has a decentralized system of government with considerable power of governance given to local self-government institutions (LSGIs). The Government of Kerala also has given instructions to the LSGIs regarding incorporation of palliative care. On 15 June 2012, Maharashtra State Government also announced a palliative care policy, making it the second state in the country to do so. Karnataka state palliative care policy was announced in November 2016 [12].

Policy options

- 1) Provide publicly funded, home-based end-of-life care for older patients who need it.
- 2) Support informal caregivers
- 3) Plan for hospital discharge in palliative care for older persons

1. Home-based end-of-life care in older patients increases the likelihood of the terminally ill dying at home, may increase patient satisfaction at one month of follow-up, but may lead to a reduction in the psychological well-being of caregivers who look after patients surviving more than 30 days.

2. Interventions to support informal caregivers may reduce the psychological distress and increase quality of life of carers but may reduce the ability of carers to cope with their role.

3. Discharge planning probably reduces both the length of hospital stays and unscheduled readmission rates at 3 months but leads to little or no difference in mortality. An integrated hospice palliative care approach could be a relatively low-cost strategy to ensure that health care providers recognize those who can benefit from hospice palliative services earlier during a life-limiting illness; have the skills to provide those services; and have timely access to specialists to support patients and families across settings (i.e., whether in the community, care facilities or hospitals).

o Given the limitations of the available evidence, rigorous evaluation and monitoring of resource use and activities are needed for all the selected options within the local context.

Implementation strategies:

A combination of strategies is needed to implement the proposed options effectively

o Improve the knowledge, competency, and care-seeking behavior of families:

Providing home-based care, using Village Health Teams (ASHA) and vocational education and training

o Improve the knowledge, competency, and attitudes of healthcare providers through educational meetings, information, education, and communications interventions

o Utilize subcontracting and cost sharing for financing

o Train community volunteers and structured referral sheets to improve referral processes

The problem

Introduction and framing of the problem

According to Population Census 2011 there are nearly 104 million older persons (aged 60 years or above) in India; 53 million females and 51 million males. As per the NSS 71st Round report (January – June 2014)]:

- The percentage of older persons was 7.7% in rural areas and 8.1% in urban areas.
- The sex-ratio (no. of female per 1000 males) among older persons was 1035 in rural areas and 1029 in urban.
- In India, during January-June 2014, about 96% of the older persons had at least one surviving child in both the sectors.
- About 61% older persons in rural and 63% aged persons in urban areas were living with their spouses.
- As many as 52% of the older persons in rural and 51% in urban areas had to depend on others for their day-to-day activity.
- Among economically dependent older persons 82% in rural and 80% in urban areas had to depend upon their children for financial support.
- About 8% of the older persons in rural and 7% in urban areas were either confined to their home or bed. For the age group 80+, 27% persons in urban and 34% in rural areas reported immobility.

The geriatric population [1] suffers from incurable diseases such as dementia, stroke, end stage Parkinson's disease, refractory cardiac failure, end stage renal failure, end stage Chronic Obstructive Pulmonary Disease (COPD) on home oxygen therapy or Non-invasive ventilation, vertebral fractures, hip fracture with poor outcomes, fragility, and poor functional status. Many of them may die in distress in the hospitals after repeated admissions. Physicians and nurses are poorly trained in delivering palliative care to this population. In addition to utilizing the health care system, most geriatric patients with functional impairment need long-term care services and supports, which can be provided in a variety of settings ranging from nursing homes to the patient's home. Access to home and community based long-term services and supports is associated with lower use of nursing homes and their associated costs. Despite the vast resources spent on geriatric patients with serious illnesses, we regularly fail to meet basic needs of this vulnerable population. Often, providers neglect to elicit patient and family goals and preferences for care and patients are shuttled through a health care system in a manner inconsistent with their values. Even when patient preferences are known, lack of home-based services or other supports leave families and providers unable to honour patient wishes.

The Ministry of Health & Family Welfare, Government of India constituted an expert group on Palliative care, which submitted its report 'Proposal of Strategies for Palliative Care in India' in November 2012.

Based on the Report, a note for 12th Five Year Plan was formulated. No separate budget is allocated for the implementation of National Palliative Care Program. However, the Palliative Care is part of the 'Mission Flexipool' under National Health Mission (NHM). A model Project Implementation Plan (PIP) a framework of operational and financial guidelines, for the states has been designed. Based on a model PIP, the states/UTs may prepare their proposals related with Palliative Care and incorporate them in their respective PIPs to seek financial support under NHM [4]. India is a federal constitutional republic governed under a parliamentary system consisting of 29 states and 7 union territories. Till the completion of this report, PIP has been made for the states of Maharashtra, Karnataka and Kerala [5].

Details of PIP:

Goal: Availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of Health Care at all levels, in alignment with the community requirements.

Objectives:

- Improve the capacity to provide palliative care service delivery within government health programs such as the National Program for Prevention and Control of Cancer, Cardiovascular Disease, Diabetes, and Stroke; National Program for Health Care of the Elderly; the National AIDS Control Program; and the National Rural Health Mission.
- Refine the legal and regulatory systems and support implementation to ensure access and availability of Opioids for medical and scientific use while maintaining measure for preventing diversion and misuse
- Encourage attitudinal shifts amongst healthcare professionals by strengthening and incorporating principles of long term care and palliative care into the educational curricula (of medical, nursing, pharmacy and social work courses).
- Promote behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community owned initiatives supporting health care system.
- Develop national standards for palliative care services and continuously evolve the design and implementation of the National program to ensure progress towards the vision of the program.

(Note: NHM flexi-pool has mandate for the activities for district level and below and hence the PIPs should be for seeking financial assistance for district palliative care unit and activities as well as state palliative care cell for implementing the program)

National Program for Health care for Elderly was launched in 2010. EFC for an amount of Rs. 288.00 Crores including 20% of State share was approved in June 2010 for the remaining period of 11th plan. The program is State oriented and basic thrust of the program is to provide dedicated health care facilities to the senior citizens (>60 year of age) at various level of primary health care [6]. The impact brought about by this program has not been measured directly. A joint statement in February 2018 was made on Palliative Care and End-of-Life Care for Older People by The Indian Academy of Geriatrics (IAG), Alzheimer's and Related Diseases Society of India (ARDSI), HelpAge India, and Indian Association of Palliative Care (IAPC).

It recommends:

- Recognizing that older persons with serious life limiting diseases including cancer and various forms of Dementia, have the right to the best possible palliative care,
- Promoting public awareness and Community participation,
- Promoting a collaborative effort between Geriatric and Palliative medicine,
- Investing in capacity building through education and training,
- Investing in research
- Establishing a platform for the exchange, comparison, benchmarking, and documentation of best practices between members.

This policy brief contributes to the evidence base of policy development for scaling up palliative care services for the older persons across India. The Ministry of Health & Family Welfare, Government of India has identified many stakeholders with relevant expertise in the field of palliative care and care for older persons (including policymakers, researchers, members of civil society, and palliative care practitioners/ geriatricians). The information and viewpoints they provided helped to define the problem, identify potential policy solutions, as well as implementation considerations. All these concerns are addressed in this report.

Background

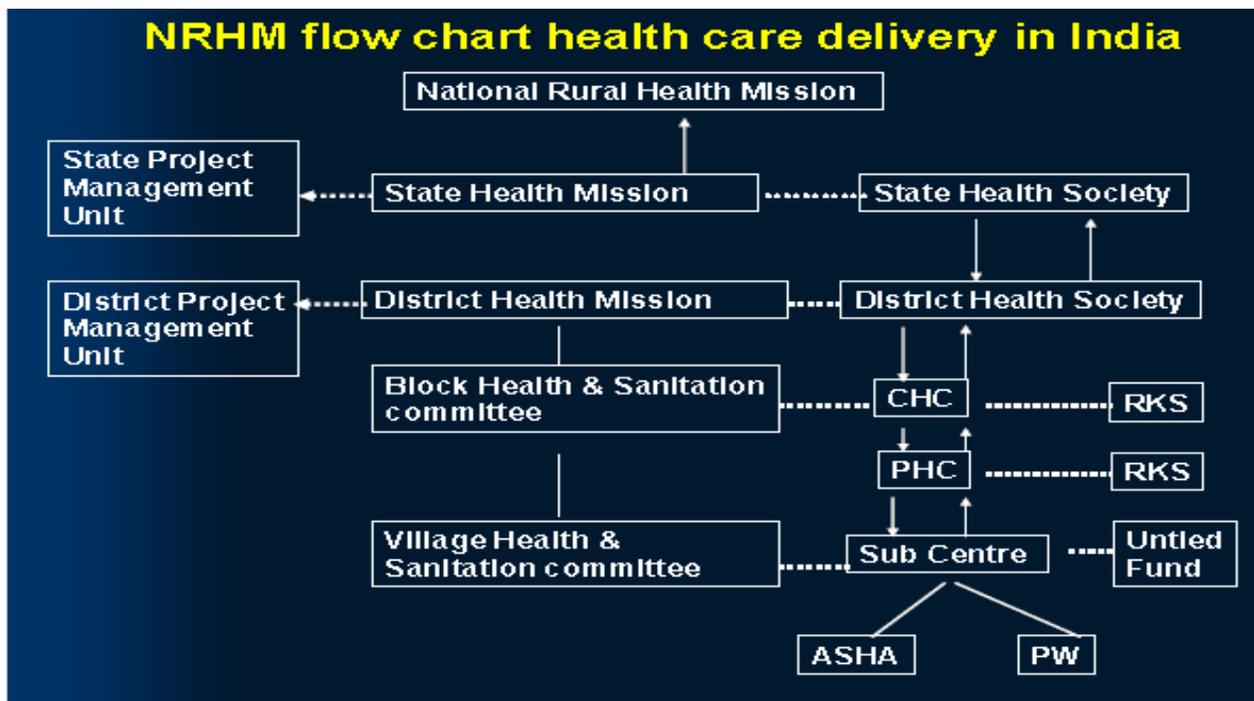
The World Health Organization (2002) has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care ... affirms life and regards dying as a normal process; intends neither to hasten nor to postpone death; ... uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated...” [10].

Hospices are an integral part of palliative care. The nurse, physician and social worker Cicely Saunders founded the modern hospice movement in 1960, which is underpinned by the key principle that holistic care should combine both teaching and clinical research pain and symptom relief. The aim of the hospice movement is to meet the physical, social, psychological, and spiritual needs of patients and their families and caregivers [7]. The concept of palliative care was introduced in India 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 Program [8]. 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]. In 2005, the World Health Assembly acknowledged the suffering of cancer patients and their families and urged its Member States to develop and reinforce cancer control programs [13]. Globally, 35 million people experience pain and suffering caused by old age or by life-limiting conditions such as cancer, AIDS, and other chronic diseases [14]. The lack of palliative care is therefore an urgent problem. Providing palliative support globally is also likely to benefit the

approximately 70 million family or voluntary caregivers who are helping those affected [15]. Developing countries account for two-thirds of the global burden [of 35 million] and a high proportion of patients in these areas are in the advanced stages of illness, with little chance of being cured [16]. The recent declaration by the World Health Assembly [17] asking all member states to integrate palliative care with routine health care comes as a major tool in advocacy and hopefully will boost the current efforts. Hopefully, it would act as a catalyst in merging/integrating the two parallel but somewhat separate efforts in geriatrics and palliative care.

A global body of scientific knowledge on palliative care interventions could be used to improve the quality of life, the process of dying, and the death of sufferers, and their affected families. Palliative care reaches only about 1% of the people in India. If we take per capita consumption of opioids belonging to the step III of the WHO ladder as a criterion, this has been on a plateau for many years now. India is still at that phase when it seems poised to leap forward, though the dynamism is yet to be manifest.

How does health care delivery work in India?



This chart does not show the heterogeneity of care [12]. As per the NSS 71st Round report (January – June 2014), more than 70% (72% in rural and 79% in urban) spells of ailment were treated in the private sector (consisting of private doctors, nursing homes, private hospitals, charitable institutions, etc.). Relatively high percentage of treatment at public hospital was reported in the rural areas of Assam (84%), followed by Odisha (76%), Rajasthan (44%), and Tamil Nadu (42%), and in the urban areas it was Odisha (54%), followed by Assam (44%) and Kerala(31%) [13].

The National Program for Palliative Care has laid down a goal of availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of Health Care at all levels, in alignment with the community requirements. This is very similar to recommendations in developed

nations with good quality palliative care service provision [11]. Some major features relevant to palliative care are:

- Healthcare Spending by the Government would double – to 2.5% of GDP by the year 2025.
- The objectives mention specifically, “Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality.”
- Community or home-based palliative care is included among the responsibilities of frontline health workers.
- Palliative care is mentioned as 1 essential feature of primary health care.
- In child and adolescent’s health, district hospitals have been specifically asked to provide palliative care.
- The policy recognizes the growing need for palliative and rehabilitative care for all geriatric illnesses and advocates for continuity of care across all levels.
- It recommends starting specialized nursing training courses in areas including “palliative care and care of the terminally ill”.
- In primary health care, particularly in urban health care, health and wellness centres are to be developed and they are to include palliative care.
- Right to healthcare is mentioned as covering ‘a wide canvas, encompassing issues of preventive, curative, rehabilitative and palliative healthcare across rural and urban areas’,
- In school health, incorporation of health education as part of curriculum is mentioned.
- The policy recommends integration of medical and paramedical education with service delivery systems.

There are some disappointments, however. Representation to the government regarding the National health policy had also emphasized the need to include palliative care into the educational curricula of medical, nursing, pharmacy and social work courses. Organizations had also requested for refining the legal and regulatory system to improve access to opioids for pain relief. These have not found a specific place in the policy document.

Size of the problem

The exact need for palliative care in older persons is difficult to estimate because of flaws in disease registration, communication difficulties, and stigma attached to the diagnosis of cancer and AIDS in specific demographic subsets [22]. It is estimated that in India around 1 million people are diagnosed with cancer every year. Around 80% of all cancers are diagnosed in the advanced stage when treatment is less effective and palliative care becomes essential [23]. Access to drugs and availability of caregivers are the most important practical issues in the management of end-of-life care. India is one of the largest legal producers of morphine, providing most of the morphine for pain relief across the world. However, the use of morphine in India is determined by the restrictions in manufacture, sale, and possession of

morphine by Narcotic Drug and Psychotropic Substance act of 1985 [24]. It is estimated that in India <3% of cancer patients have access to adequate pain relief. India ranks 67th in the list of 80 countries when it comes to the availability of painkillers for end-of-life care. Realizing the importance of making morphine available for pain relief, 14 states have amended the act to for easy availability of morphine in India [25].

India has nearly 120 million older persons with various physical, psychosocial, economic, and spiritual problems— 3.7 million suffer dementia, 40 million suffer from poor vision, 1.6 million annual stroke, 1 in 3 suffer from arthritis, 1 in 3 has hypertension, 1 in 5 has diabetes, 1 in 5 has auditory problems, 1 in 4 suffer from depression, 1 in 10 falls and sustains a fracture, 1 in 3 bowel disorder, Cancer is 10 times more common in these people. While the functionally and cognitively fit can access usual health-care facilities provided by the government, these people need active aging program to keep them independent. Health ministry has created geriatric centers and geriatric clinics in most of the states; however, these centers may not serve the functionally and cognitively impaired older persons. There is great need for mobile units, day-care centers, and hospices, and need for training of personnel in home nursing. Routine care clinics cannot handle the burden of geriatric population to address their multi-morbidity and several other age-related problems. There is a need for a rapid training of health-care professionals of various disciplines in geriatric care. Government must support nongovernmental organizations and other agencies which provide day care, home care, and palliative care so that these services become affordable to all the older persons [26].

Kerala, an Indian state, is cited as a 'beacon of hope' for providing palliative care services. Constituting only 3% of India's population, Kerala provides two-thirds of India's palliative care services. The state has a formal palliative care policy in place and its government provides funding for community-based care programs. It was also one of the first of India's states to relax narcotics regulations to permit use of morphine by palliative care providers. Recognizing the need of palliative care as primary healthcare and the importance of homecare services, the neighbourhood network in palliative care was commenced as a community-run system that operated through local micro-donations. The volunteers identify those in their community who need care and supplement the work of healthcare professionals linked to the state's 230 local palliative care units covering a population of 12 million. The volunteers can provide psychological, social, and spiritual support after initial training [27].

It is estimated that in India the total number of people who need palliative care is likely to be 5.4 million people a year, stressing on the need to expand the coverage of palliative care services and integrate services at all levels of care [28]. Though there is limited data, older persons will contribute to a substantial amount in that.

Models of care

Palliative and geriatric care models improve value by both increasing quality and decreasing costs. These care models, centred around matching care to patient-centred goals, have been found to improve symptom burden; quality and length of life; and patient, family, and provider satisfaction. Cost reductions have been found related to many outcomes important to policymakers, including decreased hospital costs; decreased hospitalization, emergency department, and intensive care unit rates; reduction in 30-day readmission rates; and decreased hospital mortality [19].

Most successful models involve some degree of care management. Some are focused on increasing safety and patient-centred care in the inpatient setting, such as Acute Care for the Elderly (ACE) units,

the Hospital Elder Life Program (HELP), Nurses Improving Care to Health System Elders (NICHE), and palliative care consult services. Care transitions programs seek to reduce readmissions to the hospital. The Hospital at Home program allows some patients with acute illness to entirely avoid a hospitalization [20]. Coordination of care among multiple specialists and settings is a challenge for this patient population. Geriatric Resources for Assessment and Care of Elders (GRACE) and Guided Care are two examples of interdisciplinary programs that have established a record of accomplishment for increasing coordination of care for older patients with multiple chronic conditions [21].

Much of the intent of these programs is to overcome both the balkanized health system—hospital, outpatient practice, nursing home, assisted living, hospice—and the disconnect between medical disciplines—primary care providers, hospitalists, cardiologists, oncologists, surgeons, and other specialists—that can frustrate and confound patients. Because there is no payment mechanism to support them, the “best practices,” exemplified in these models and others, have been difficult to scale up and have not reached the large numbers of patients who could benefit from them.

Historical context in India

The first formal palliative care service in India was initiated in 1986 as a hospice in Mumbai. Pain clinics offering outpatient services were in existence in some of the cancer centres since late 1980s. From the 1990s onwards, there was a significant increase in the momentum of development of hospice and palliative care provision. This was demonstrated through both an expansion in the number of services as well as other key events and initiatives. Pain and Palliative Care Society, a civil society organization, initiated an outpatient palliative care clinic and home care services in Calicut (Kerala) in 1993. Another NGO, CanSupport, founded in 1997 in Delhi started providing the first free palliative care home care support service in North India. Cipla Cancer Palliative Care Center was established in Pune, Maharashtra, (Central India). Four nongovernment organizations (NGOs) in Kerala joined together in 1999 to launch Neighborhood Network in Palliative Care (NNPC), a major community-owned initiative in palliative care. NNPC continued to grow to become an extensive network covering most of Kerala. The government of Kerala took a major step to support development of palliative care by declaring palliative care as part of Primary Healthcare in the state through an official government policy in 2008. Indian Association of palliative Care, the umbrella organization for palliative care in the country, was formed in 1994 in consultation with World Health Organization and government of India.

Present day

There are several non-profit NGOs that have palliative care as their primary mandate. Most NGOs providing for care are run by volunteers, with resources from charities, national/international funding agencies and other NGOs, and in some instances, through payments from patients. Institute of Palliative Medicine in Calicut (Kerala) was designated in 2010 as the first WHO collaborating centre in palliative care in low-income and middle-income countries. This was followed an year later by designation of another palliative care centre in the state as WHO Collaborating Center for Training and Policy on Access to Pain Relief.

There are less than 1000 palliative care units in India. Less than 10 of them are conventional hospices. The distribution of services, quality and access to care differs. Over 90% of all palliative care programs in the country are available in the state of Kerala with 3% of the country's population. There are few states in the country without a single centre for palliative care service provision.

Local and state governments play a major role in running palliative care services in Kerala. In most of the other regions, services are managed by NGOs.

Kerala Model

The state of Kerala has managed to develop an integrated health service delivery model with community participation in palliative care. The evolving palliative care system in Kerala tries to address the problems of the incurably ill, bedridden, and dying patients irrespective of the diagnosis. It is also expanding to areas of community psychiatry and social rehabilitation of the chronically ill. The primary healthcare system in Kerala plays a major role in these activities.

The main components of Kerala's program are:

1. Community mobilization and ownership by the local community
2. Involvement of the local self-government institutions (LSGIs)
3. Incorporation of palliative care in the primary healthcare system

The major player in development of this public health model in palliative care in Kerala has been LSGIs in the state [14].

Problems with pan Indianisation of the Kerala model

- Low awareness among public, handful efforts various civil society organizations in the field, scant support by the media and lack of program implementation by NHM.
- Lack of policy recognition, low awareness at the political level.
- State funding for palliative care through NHM, Ministry of Health, local self-governments are in a shared flexi-pool.
- Lack of coordination between governmental and nongovernmental agencies, no broad vision or long-term commitment.
- Improperly mechanised decentralized system of Governance in various parts of the country.
- Lack of Home care, either nurse based, or doctor based, who would lead the care process and link institutions to patients' homes.

Cause of the problem

Some generic causes

- Lack of political will, disparities between states, capacity of human resources for health, infrastructure, level of access and quality of palliative care
- Economic deprivation in a large segment of population results in poor access to health care.
- Poor educational status leads to non-utilization of scanty health services and increase in avoidable risk factors.

- Lack of environmental sanitation and safe drinking water, under-nutrition, poor living conditions, and limited access to preventive and curative health services
- Lack of education, gender inequality and explosive growth of population contribute to increasing burden of disease
- Expenditure on health by the Government continues to be low. It is not viewed as an investment but rather as a dead loss!
- States under financial constraints cut expenditure on health
- Wide urban-rural gap in the availability of medical services, inequity at all levels
- Poor facilities even in large Government institutions compared to corporate hospitals (Lack of funds, poor management, political and bureaucratic interference, lack of leadership in medical community)
- Private practitioners and hospitals major providers of health care in India
- Practitioners of alternate systems of medicine also play a major role, but their practices are often unregulated
- Concerns regarding ethics, medical negligence, commercialization of medicine, and incompetence
- Increasing cost of medical care and threat to healthy doctor patient relationship
- Existing infrastructure for health care needs to be strengthened. Health should be perceived as an investment and receive greater budgetary allocation
- Education, safe water, and sanitation need priority
- Vaccination coverage to be improved
- Better implementation of national health programs
- Judicious use of the scant resources by promoting most cost-effective strategies for disease prevention
- Inclusion of all level of stakeholders in planning and policy making using tremendous human resource available in the country

Specific causes

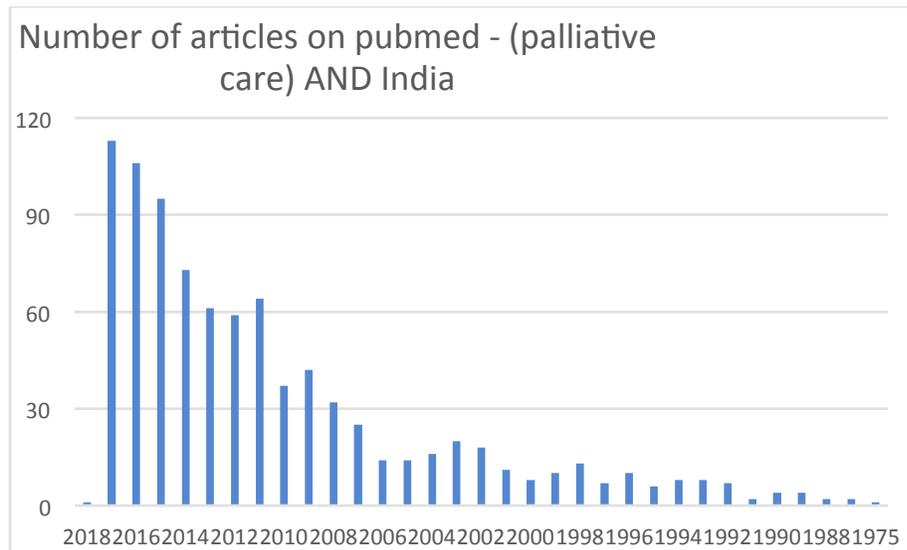
The burden of palliative care for the older persons in a country may be influenced by several factors, both at the community and the health systems levels.

Several trends in health care today decrease the chances of cancer patients having access to palliative care. These range from the limited availability of palliative care services to the philosophy of patient care that dominates our health care system. Most patient care is disease-oriented. Palliative care can assist in changing from a disease-focused approach to a patient-centred philosophy, where the needs of the patient and the patient/family goals are essential to planning care. Patient-centred care broadens

the focus and requires clear coordination across specialties and disciplines and access to palliative care physicians and nurses. The goal of palliative care should continue to focus on the relief of suffering and the improvement of the quality of life for patients with advanced illnesses [29]. Importantly, the problem of inadequate pain relief is also owing to the poor availability of morphine, lack of skills among professionals to prescribe morphine, fear of side effects, and a fear of addiction of morphine among professionals, patients, and their family [30].

Another aspect of care that is clearly lacking in current health care systems is the communication about patient goals and preferences for care. When patients are asked what kind of care they want when serious and life-threatening disease occurs, their preferences include pain and symptom control, avoidance of prolongation of the dying process, a sense of control, concern for family burden, and an opportunity to strengthen relationships with loved ones. However, research does not demonstrate that patients' preferences are adequately met [31].

An additional challenge to implementation of palliative care is the limited evidence for this specialty. Studies are needed that provide evidence to guide better decisions regarding symptom management, different health care models, decision-making approaches about treatment options, communication on sensitive topics such as death, and support for family caregivers. The existing strength in India, i.e. IAPC, the Indian Journal of Palliative Care, palliative care facilities (government hospitals, NGO run facilities, Profit based/ corporate centres), geriatric care organizations/ journals, experts and professionals in this field should be jointly utilized to mount coordinated research activities in palliative care.



Number of articles on PubMed - (palliative care) AND India AND geriatric/ older person are 10 or less (as on 04.02.2018).

Medical insurance does not play a significant role in hospice and palliative care provision in India. With a small number of healthcare professionals struggling to attend to millions and millions with various diseases, it is difficult for the average doctor to set aside time from his curative practice for palliative care [32].

The Policy Environment

Provisions in Indian constitution

In the reasoning of John Rawls' "A Theory of Justice", there are two principles that aptly turn the wheels on situating palliative care. Firstly, under the veil of ignorance, information is kept from each other relating to identity, gender, host of experiences, disabilities or one's belonging to society to diminish prejudices, and secondly, when people are reduced to original position and everyone functions at the same level by ignorance of knowledge that very much defines them, they can meet their basic social and economic needs. This results in a just and fair system which is quintessential at the point of pulling the plug, to patients and care givers alike at that moment, nothing else matters [15].

Although, Rawls' conjectural tinges may be idealistic, when health is concerned, human rights and dignity should be the utmost priority. The framers of the Indian Constitution were influenced by the concept of human rights and guaranteed Indian citizens most of human rights contained in the Universal Declaration of Human Rights. They incorporated civil and political rights into Part III of Indian Constitution, and health, education, and cultural rights into Part IV as "Directive Principles of States Policy". The inclusion of important provisions of Universal Declaration of Human Rights in the Constitution of India has given them supremacy over all other statutory provisions. The vein of the Indian Constitution is in Article 21 called 'Right to Life' and reflective of how delicately human rights should be preserved. India is also part of the treaty to Article 7 of the International Covenant on Civil and Political Rights that states "...no one shall be subjected to torture or to cruel, inhuman or degrading treatment [16]."

Availability of Internationally Controlled Essential Medicines

On the Occasion of World Cancer Day 2012, Pallium India, International Association for Hospice and Palliative Care (IAHPC), Pain & Policy Studies Group, University of Wisconsin / WHO Collaborating Center for Pain Policy and Palliative Care (PPSG) made some important declaration:

Considering that the 2011 United Nations political declaration on non-communicable diseases calls for member states to promote the use of affordable medicines, including generics, for palliative care;

Considering the World Health Organization's recommendation that essential medicines should be available to patients at all times and at a price the individual and the community can afford;

Recognizing that morphine is the only strong opioid analgesic included in the WHO Model List of Essential Medicines;

In the light of the available scientific evidence that immediate release oral morphine is both safe and effective as first-line treatment for severe pain;

Finding that immediate release oral morphine is less expensive for patients than sustained release morphine and most other strong opioid formulations;

Aware that in many institutions, particularly in low and low-middle income countries, immediate release oral morphine is not available, while opioid formulations that are more expensive (or more difficult to use, such as injectable morphine) are available;

Considering that the high cost of opioids hinders access to treatment to the vast majority of patients in many low and low-middle income countries, resulting in millions of patients suffering needlessly with untreated pain;

Recognizing that the low profit margin typically realized from selling immediate release oral morphine is often made worse by the additional costs of unnecessarily burdensome regulatory requirements, which may further deter the pharmaceutical industry from supplying immediate release morphine,

DECLARE that denial of adequate pain treatment to significant numbers of patients violates the right to the highest attainable standard of physical and mental health, as articulated in article 12 of the International Covenant on Economic, Social and Cultural Rights, and may violate the prohibition of cruel, inhuman, or degrading treatment⁸ as articulated in article 7 of the International Covenant on Civil and Political Rights; and

DECLARE that the exclusive availability of sustained release morphine and other expensive or injectable opioid formulations hinders access to an essential health service, leading to poor clinical and public health practice.

WE CALL UPON GOVERNMENTS, PHARMACEUTICAL INDUSTRY AND HEALTH CARE INSTITUTIONS to guarantee the accessibility of immediate release oral morphine to patients in need at a cost that the individual and community can afford. In particular:

Governments should ensure that immediate release oral morphine is always available in public healthcare institutions before other more expensive opioid formulations become available. Where more expensive or injectable opioid formulations are already available and immediate release oral morphine is not, they should take immediate steps to ensure that it becomes available.

Governments should work collaboratively with private healthcare institutions and the pharmaceutical industry to ensure the widest possible availability and accessibility of immediate release oral morphine in the private healthcare system.

Governments should minimize the impact of regulatory requirements on the manufacturing, importation, exportation and distribution of opioid analgesics and work with the pharmaceutical industry to facilitate the availability of immediate release oral morphine [17].

But, long back in the early 1990s that an appeal was made, both in India and globally, for access to palliative care to be treated as a human rights issue. Over the past few years, India has witnessed robust advocacy efforts which push for the consideration of palliative care and pain management as a human right. Central to this is India's Narcotic Drugs and Psychotropic Substances (NDPS) Act, 1985: its genesis, its critique, and the amendments aimed at enhancing access to the NDPS for medical care and research.

Genesis of the NDPS Act, 1985 and its key features

In India, statutory control over narcotic drugs was provided by three legislations – The Opium Act, 1857, The Opium Act, 1878 and The Dangerous Drugs Act, 1930 – until the enactment of the NDPS Act, 1985. However, the statutory provisions of the NDPS became inadequate in the light of the growing trafficking of illicit drugs; the emergence of various new international laws and conventions, such as the UN Single

Convention on Narcotic Drugs 1961, the Convention on Psychotropic Substances 1971, and the Convention on Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988; and treaties concerning NDPS. India, being a signatory to these conventions or treaties, was bound to revisit her own NDPS-related legal instruments. Besides, a number of deficiencies were noted in the laws in India. For example, the scheme of penalties for offences was an inadequate deterrent in the face of the stronger international gangs engaged in drug trafficking. The failure to prescribe a minimum punishment sometimes forced the courts to let off the offenders. Further, no arrangements had been made to address the drug traffickers' increasing use of Indian territory as a site of transit of controlled drugs. There were no provisions allowing officers from various Central enforcement agencies, such as Narcotics Customs and Central Excise, to investigate drug trafficking and abuse offences under the existing laws. In the absence of any comprehensive legal instrument to control the abuse of NDPS, the government was also finding it difficult to address the emergence of addiction to psychotropic substances, such as amphetamines, as opposed to conventional opioids, such as morphine. These factors together necessitated a new statutory instrument, which would appropriately consolidate the three existing Indian laws, and fitting amendments. In response, the NDPS Bill, 1985 was presented to the Lok Sabha on August 23, 1985. It was enforced on November 14, 1985 as the NDPS Act, 1985 (61 of 1985). This Act aims to prevent abuse of NDPS; and prohibit trade in and the cultivation, production, possession, sale, purchase, use and consumption of NDPS, except for medical and scientific purposes under licence [18].

Critique of the NDPS Act, 1985

The NDPS Act, 1985 was shaped and implemented with the “war on drugs” approach. It failed to acknowledge the principle of balance, that is, it did not succeed in ensuring the availability of NDPS for medical purposes while preventing their abuse. On the substantive front, the Act has many excessively stringent features, such as the denial of safeguards for civil liberties that are normally available within the criminal justice system. Another such feature is the mandatory death penalty for particular repeat offences involving large quantities of drugs. These features make the NDPS Act, 1985, one of the harshest legal instruments in India. The provision of the death penalty has been critiqued on the ground that it infringes the individual's fundamental right to life and liberty as per Article 21 of the Constitution of India. This and the provision of enhanced punishment for offences after previous conviction have also been criticized for their inappropriateness and non-proportionality. For example, drug trafficking is only an economic offence. Therefore, it cannot and should not attract the death penalty which, theoretically speaking, is considered appropriate for those who have committed the offence of taking a human life. Procedurally, the availability of NDPS for patients in need of pain relief was hampered by the lack of standardized rules across the states. In addition, if a healthcare facility or pharmacy wished to procure, stock and dispense NDPS for medical purposes, it was required to secure 4–5 licences from various ministries/government departments. To make matters worse, acquiring these licences – which were valid for limited periods – concurrently from the various departments concerned was a painful process, given the slow-paced and inefficient Indian bureaucracy. The stringent licensing requirements, bureaucratic hurdles, excessively harsh and disproportionate penalties, and criminalization of drug use, combined with the fact that there was little scope for seeking bail and/or for repeals, imposed a restrictive regulatory regime for controlled medicines. Data indicate that the medical use of morphine fell by 97% after the enactment of the Act. A review by Human Rights Watch of human rights practices around the world between November 2012 and November 2013 stressed the need for reforms in the

regulatory environment for drugs [19]. The adverse fallout of the NDPS Act, 1985, and reviews such as the one cited above shaped advocacy efforts which led to amendments to the Act.

Narcotic Drugs and Psychotropic Substances (Amendments) Act, 2014

The NDPS Act, 1985 has been amended thrice. The most recent amendments were approved by the President of India on March 7, 2014. The first amendment (1989) made the Act even more stringent, while the second one (2001) partially repaired the damage done by the first. The amendments of 2014, which were ratified on March 7, 2014, were motivated by the need to address the restrictive and stringent regime introduced by the NDPS Act of 1985. They have made the Act more suitable for the needs of healthcare providers and pharmacies with regard to the use of NDPS for medical and scientific purposes. This should help in addressing the need for easier access to controlled drugs for pain management and PC. The recent amendments were driven by civil society, including those deeply involved in the provision of PC as well as patients and their family members.

The specific amendments ratified in 2014 are as follows:

- A new category of “essential narcotic drugs” [section 2 (viiiia)] will be created. This will enable the Government of India to notify a list of such drugs that is relevant and feasible for use in medical practice. These drugs will be subject to the Central Rules [Section 9(1) (a)] and, therefore, will apply uniformly throughout the country. This eliminates the need for the cumbersome practice of securing licenses from multiple state departments before the drugs can be efficiently dispensed for beneficial use.
- The restraints on bail in drug offences will be relaxed.
- The mandatory death penalty for those previously convicted for certain offences will be revoked.
- Central to these amendments is their alignment with the international regulations on drug control. This creates a better balance between drug control and the availability of drugs for beneficial use. It is also hoped that the recent amendments will offer the medical and scientific community more opportunities for research on the drugs to enhance their beneficial use.

How was it done?

The advocacy efforts in India for legal reforms were shaped by the growing recognition worldwide of patients’ need to have access to NDPS for pain relief in wide-ranging health conditions at various stages of recovery, as well as that of being terminally ill. Eventually, these efforts gathered momentum and the drug user activists, who were driven by the ‘harm reduction’ approach, called for amendments to the Act. These activists advocated for treatment for drug dependence, rather than victimization of drug users. These issues were raised through legal means, such as public interest litigation (PIL). Advocacy for PC was also carried out by those who were in favor of increasing access to drugs for medical and scientific purposes. This necessitated easing of procedural matters and facilitating the process of securing licenses for acquiring, stocking and dispensing NDPS. Through a joint action taken by PC activists in collaboration with others, the rules of the various states were simplified in 1998 as per the instructions of the Department of Revenue. This was only partially beneficial, considering that it took a period of 15 years to simplify the rules in 16 states. A watershed was reached in 2007, when a PIL was

filed by the Indian Association of Palliative Care (IAPC) in collaboration with cancer patients in need of adequate access to pain relief, or their families. Subsequently, in June 2012, representations were filed by civil society groups (including Pallium India, the IAPC and Lawyers' Collective) with the Department of Revenue, Ministry of Finance and Standing Committee on Finance about the amendments they considered necessary. This paved the way for the latest amendments. The global scenario vis-à-vis access to controlled drugs has witnessed a change in thinking over the past decade, particularly since 2008. This had a great impact on the push for progressive reforms in the NDPS Act, 1985. The issue of peoples' access to PC gained much-needed visibility when those involved in advocacy efforts were able to draw upon appropriate UN Conventions and utilize the two mutually reinforcing arguments, "lack of access to palliative care is a human rights concern" and "governments' inability to offer pain relief amounts to torture". The new paradigm also underscored the need to make PC an integral part of the notion of the right to healthcare. Because of these developments, the need was felt to change the regulatory environment created by the NDPS in a manner that would strike the right balance between "drug abuse" and "drug use for beneficial purposes".

Challenges ahead

The NDPS Amendment Act is simplified now but needs to be implemented by state governments.

Palliative Care as a Human Right

Between 2000 and 2007, at least six important statements or declarations on PC were made in different parts of the world. Each of these explicitly asserted the need for access to palliative care as a human right. Most of them emerged in the context of cancer and HIV/AIDS care. They were initiated by professional associations, advocacy groups or non-governmental organizations involved in the care of cancer and HIV/AIDS patients. The growing acceptance, globally, of the argument that access to PC and pain relief is a human rights issue was a response to the increasing misery wrought by the HIV/AIDS epidemic. For example, it was the joint declaration and the statement developed and signed by representatives of numerous international and regional organizations, both from the North and the South, at the XVII International AIDS Conference in Mexico City in 2008 that provided further momentum to the "palliative care as human rights" discourse. Although access to PC was recognized as a human rights issue in India way back in 1994, the global shift gave the advocacy for legal reforms a much-needed fillip and the efforts were expedited in 2011. India was at the forefront of various advocacy efforts at the global level through several international networks and initiatives, which were focused solely on enhancing people's access to PC and pain treatment. Some of these are the International Association of Hospice and Palliative Care (IAHPC), International Federation of Health and Human Rights Organisations (IFHHRO), Human Rights Watch (HRW), International Psycho-oncology Society (IPOS) and Worldwide Palliative Care Alliance (WPCA). These efforts were aimed at raising the issue at the UN and WHO platform. Articles 5 (recognition of the rights to life, and to freedom from torture and cruel, inhuman or degrading treatment) and 25 (recognition of the right to a standard of living adequate for health and well-being) of the Universal Declaration of Human Rights of 1948, and General Comment 14 of paragraphs 12 and 34 of the UN Committee on Economic, Social and Cultural Rights (22) formed the solid foundation of the argument in favor of integrating PC into the right to healthcare. The Committee stated that parties are "under the obligation to respect the right to heal by, inter alia, refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services". It also underscored the importance of enabling chronically and terminally ill

persons to die with dignity by attending and caring for them. Subsequently, a logical and yet more forceful argument drew upon the UN Convention against Torture: “Inability of the governments and healthcare systems to offer palliative care amounts to torture by subjecting individuals to unnecessary pains or pains that can be alleviated fully or partially”. Because of this, the issue of access to PC and pain treatment found mention in the reports of both Special Rapporteurs on health in the year 2008, and on torture in 2009 and 2013. Mendez, the Special Rapporteur on Torture since 2010, held that the lack of availability or denial of pain treatment in healthcare settings amounted to torture on three grounds: (i) the severity and extent of suffering warrant the provision of pain treatment to everybody, without any discrimination; (ii) the state is unaware of unnecessary suffering and the fact that no pain treatment is being offered, despite the robust guidance and protocols provided on such treatment by WHO and others; and (iii) the state has no reasonable justification for not providing pain treatment. These developments at the global level lent visibility to the issues related to limited or no access to PC and the scale and severity of the problem[20].

Multi-lateral global

There have been many notable international events where palliative care and access to opioid medications have been discussed and successfully adopted in policies for mainstream health care, like:

- 2017 WHA cancer resolution: From global commitment to national action
- WHA67.19 - Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course. WHA Resolution; Sixty-Seventh World Health Assembly, 2014
- The draft 13th General Program of Work was discussed by WHO’s Executive Board on 22-27 January and a revised version was issued. The 71st World Health Assembly will consider the draft 13th General Program of Work in May 2018.
- UNGASS “Outcome Document” and UNGA Resolution on the World Drug Problem (Chapter Two on Controlled Medicines), 2016: *“We note with concern that the availability of internationally controlled drugs for medical and scientific purposes, including for the relief of pain and suffering, remains low to non-existent in many countries of the world, and we highlight the need to enhance national efforts and international cooperation at all levels to address that situation by promoting measures to ensure their availability and accessibility for medical and scientific purposes, within the framework of national legal systems, while simultaneously preventing their diversion, abuse and trafficking, in order to fulfil the aims and objectives of the three international drug control conventions”*
- In 2015, countries adopted the 2030 Agenda for Sustainable Development and its 17 Sustainable Development Goals. Among them, Goal 3: Ensure healthy lives and promote well-being for all at all ages
- The Open-Ended Working Group on Ageing was established by the General Assembly by resolution 65/182 on 21 December 2010. Its 9th Session will be held in July 2018
- CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)

- Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment jointly recognized that a failure to address barriers to palliative care and pain treatment can be a violation of human rights
- In May 2014, the Human Rights Council appointed the first Independent Expert on the enjoyment of all human rights by older persons (HROP). “Palliative care is not only about lifting older persons out of needless pain and distress; it is an imperative to maintain their dignity at the end of their lives,” the human rights experts said, noting that the number of older persons is expected to more than double globally from 841 million people in 2013 to more than 2 billion in 2050.
- A world first: religions together for Palliative Care for older people. On March 30th, 2017 representatives from all the major religions, human rights activists, doctors, patients and families met in Rome at Pontifical Academy for Life (Vatican City) and created and signed the “Religions of the World Charter for Palliative Care for Older People”: a document of global value.

Palliative Care: National Policies / Laws

During 2012, the Ministry of Health and Family Welfare developed a National Palliative Care Strategy. Following the creation of the National Strategy, Pallium India, with support from WHO (India), organized a working group meeting at Trivandrum in January 2013 to develop a framework for implementation of the palliative care strategy. The draft framework created by the working group was submitted to WHO (India) for operational analysis, as decided at the working group meeting. Palliative care was included in the National Health Policy 2017 [12]. The Catholic Health Association of India (CHAI) signed a MoU with Pallium India in September 2017 [21].

National policy context and achievements

The Government of India has announced the National Health Policy 2017. Some major features relevant to palliative care are [11]:

- Healthcare Spending by the Government would double – to 2.5% of GDP by the year 2025.
- The objectives mention specifically, “Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality.”
- Community or home-based palliative care is included among the responsibilities of frontline health workers.
- Palliative care is mentioned as 1 essential feature of primary health care.
- In child and adolescent’s health, district hospitals have been specifically asked to provide palliative care.
- The policy recognizes the growing need for palliative and rehabilitative care for all geriatric illnesses and advocates for continuity of care across all levels.
- It recommends starting specialized nursing training courses in areas including “palliative care and care of the terminally ill”.

- In primary health care, particularly in urban health care, health, and wellness centers are to be developed and they are to include palliative care.
- Right to healthcare is mentioned as covering 'a wide canvas, encompassing issues of preventive, curative, rehabilitative and palliative healthcare across rural and urban areas',
- In school health, incorporation of health education as part of curriculum is mentioned.
- The policy recommends integration of medical and paramedical education with service delivery systems.

There has been no formal National policy review on palliative care/ geriatrics in India till date and experts have raised some disappointments. Representation to the government regarding the National health policy had also emphasized the need to include palliative care into the educational curricula of medical, nursing, pharmacy, and social work courses. We had also requested for refining the legal and regulatory system to improve access to opioids for pain relief. These have not found a specific place in the policy document. In this grim scenario, amalgamation of palliative care with geriatric care seems to be a distant dream.

Palliative Care: State Policies / Rules

India has 28 states and 7 Union Territories. Health care is the responsibility of the State Government, each state creating its own policy. On April 15, 2008, Kerala announced a State Palliative Care Policy, integrating palliative care into the government's healthcare system. Kerala State has a decentralized system of government with considerable power of governance given to local self-government institutions (LSGIs). The Government of Kerala also has given instructions to the LSGIs regarding incorporation of palliative care. On 15 June 2012, Maharashtra State Government also announced a palliative care policy, making it the second state in the country to do so. Karnataka state palliative care policy was announced in November 2016 [12].

Challenges

Non-government palliative care organizations, who already are struggling with paucity of resources, will have to take the onerous task of finding funds and personnel for catalysing government action, state by state, through 29 states and six union territories. Despite a submission before the Supreme Court of India expressing willingness to incorporate palliative care in undergraduate curricula, and despite the palliative care community preparing the curricula and giving a framework for implementation, the Medical Council of India and the Indian Nursing Council are yet to act on the matter. Though the National Program in Palliative Care was created in 2012, due to lack of budget allocation, only a tiny part of the program has been implemented. Even for the part that is funded, considerable catalytic work is needed with the state governments to ensure that proper plans are made and implemented. In short, some major barriers to access to palliative care in India have been overcome, but implementation of created policies and laws still requires massive efforts by both the government system and non-government organizations. The non-government organizations do have the commitment but would need international support to effectively facilitate government activity. The concentration of risk and spending for older adults with both chronic disease and functional impairment presents a compelling case for the integration of principles of geriatrics and palliative care practice. Improving care quality and

preventing predictable crises reduces use of costly emergency departments, hospitals, and nursing homes [22].

Policy options

National stakeholders (see Annexure I) involved with the provision of palliative care have attempted to identify potential policy solutions that can aid the scaling up of palliative services for the older persons within the health system [33]. To this end, attempts have been made to summarize the best available evidence for some of the interventions proposed, but many potential options still require further rigorous investigation.

The three policy options presented in this section can potentially be adopted independently, but they also complement one another. Home-based care increases the probability that terminally ill patients will experience a peaceful death surrounded by their loved ones and improves the quality of life of informal caregivers. Discharge planning also helps to reduce unscheduled admissions and may also free up capacity for acute care services.

Policy Option 1:

Home-Based Palliative care for older persons

Home-based specialist palliative care services are developed to meet the needs of the patients in advanced stage of cancer at home with physical symptoms and distress. Specialist home care services are intended to improve symptom control and quality of life, enable patients to stay at home, and avoid unnecessary hospital visits. This can often lead to a good End of life care. This refers to the period when it has become obvious that death is inevitable and imminent. The primary aim of any treatment at this stage is to improve the patient's quality of life as opposed to extending length of life or curing the illness [34]. It can be a good idea for India to invest in health services to provide care at home for patients with terminal illness, as the public health services are overburdened [35,36].

Status of Home-Based Care

India has the second largest geriatric population in the world. According to a United Nations Population Fund report, the number of people age 60 and over in India will increase from 100 million in 2011 to 300 million by 2050; this means one in five Indians will be above the age of 60. Of the 300 million over-60s, 200 million are likely to be suffering from chronic ailments. Already, non-communicable diseases including cardiovascular diseases, diabetes, chronic obstructive pulmonary disease, and cancer cause around 50% of all deaths in India. The concept of old-age homes or assisted living is socially largely unacceptable in India and therefore better home-based health care facilities are becoming an imperative. It is estimated that for an average individual, 70% of health care needs can be met in the home environment. This can result in better health outcomes and lower medical costs for the patients [37].

Most home-based care in India is offered through private providers, most of which are in central or urban regions. Necessarily, much of the population are unable to utilize such services. There is a need for public investment to further integrate home-based care within the mainstream health system and to find ways to overcome such barriers. In this regard, India has deployed nearly 10 lac Accredited Social

Health Care (ASHA) workers representing transformational change agents. The ASHA workers act as mobilizers for institutional deliveries, focus on integrated management of neonatal and childhood illness and advise on home based neo-natal care. The NHM has also empowered people through Village Health and Sanitation Committees to formulate village health plans and exercise supervisory oversight of ASHA workers. At the Primary Health Centre (PHC) and Community Health Centre (CHC) level Rogi Kalyan Samitis have been activated to establish systems of oversight over the public health facilities for creating a patient friendly institution. Besides rural areas, the urban slums are now receiving attention with the launch of the National Urban Health Mission [11]. Delegating palliative care for the older persons to these functionaries might overburden the system and new avenues needed to be thought of.

Impact of Home-Based Care at End-of-Life for older persons

A study in a tertiary academic cancer hospital in India showed that, specialist home-based palliative care improved symptom control, health-related communication, and psychosocial support. It promoted increased number of home-based death, appropriate and early hospice referral, and averted needless hospitalization. It improved bereavement outcomes, and caregiver satisfaction [34]. These findings have been echoed by a systematic review done on 23 studies (16 RCTs, 6 of high quality), including 37,561 participants and 4042 family caregivers, largely with advanced cancer but also congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), HIV/AIDS and multiple sclerosis (MS), among other conditions [38]. Though these articles were not directed specifically to older persons, majority of the people included were old.

Relevance of the research findings to the Indian context

Applicability

The systematic review was conducted in high-income settings with established palliative care provisions. The applicability of this evidence to low- and middle-income settings such as India may not be the same, but the Indian study corroborates many findings. Still, it is important to consider the heterogeneous composition of the country and the massive inequalities of health scenarios in urban and rural areas in India. From that point of view, the impact may be substantially different.

Equity considerations

The review did not provide data on the differential effects of home-based care for disadvantaged groups such as those living in rural areas, the poor, the old, children, or women with progressive illnesses. Possible harm may be caused with exclusive home-based care if it reduces the appropriate use of hospital care and thereby increases complication rates, particularly among disadvantaged populations.

Costs and cost-effectiveness

The review acknowledged that more work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.

Monitoring and evaluation

The monitoring and evaluation of the effects of home-based care is urgently needed in the Indian context. Attention should be given to the impact of differential effects on disadvantaged socio-economic groups, as well as the local costs of the intervention, and its cost-effectiveness. Contextual outcome measures might help to capture the relevant metrics in this aspect.

Policy Option 2:

Supporting informal caregivers

Informal or unpaid caregivers in palliative care, include family, friends or volunteers offering support to patients who are unable to cope on their own. People who care for patients with a progressive illness may themselves suffer from many ailments, including sleeplessness, a general deterioration in health, exhaustion, anxiety, and depression. In India, with limited social support from the government, most of the care is provided by informal care givers [39].

literature review undertaken by Harding et al., 2011 identified five key forms of interventions for providing support for them [40]:

- o Psychological support: The use of psycho-educational sessions for individuals or for families; telephone interventions; cognitive-behavioral interventions such as stimulus control, relaxation, cognitive therapy, sleep hygiene; music therapy; and home visits
- o Palliative care/hospice services: Formal caregivers providing assessments and care to both the patient and family, at home or at health facilities
- o Information and training: Training for caregivers in home care and symptom management and use of informational materials Respite services: Such as coping skills training programs, and at-home palliative care respite services
- o Physical interventions: Activities such as yoga exercises.

Support for carers potentially protects their health and well-being and may also help to improve the quality of care provided to the patients who depend on them. The needs of carers may vary throughout the period of caregiving and in the phase of after death bereavement, and so health professionals should be well equipped to provide the necessary support.

Status of supporting informal caregivers

About 30 years ago, the role of a caregiver in India was naturally accepted, as the older generation lived with the children. The older persons looked to the young members of the family not for physical assistance alone, but for psychological support as well. Consequently, they kept better health. As for caregiving, the onus was not on a single person, the family members took turns in caring for the young, the ill and the older persons. But, today's scenario has undergone a sea change. Nuclear families and old parents living alone — fending for themselves and living with unaccountable fears and grave illnesses — are the order of the day. The network of mostly private, together with public, providers mentioned earlier take on the dual role of caring for both patients and their families or carers [5]. So, we should be cautious in not focusing the entire thrust of specialist palliative care services upon the patient, but also

to accommodate the needs of caregivers. This is a sector where there is little research in India, and good quality studies are needed [41].

Impact of supporting informal caregivers

A good systematic review conducted by Candy and colleagues (2011) assessed a range of supportive programs for caregivers, including psychological support and practical assistance [42]. The review found that supporting informal caregivers during the terminal phase of a patient's disease compared to usual care may:

- Reduce psychological distress in informal caregivers
- Increase the quality of life of carers
- Reduce the ability of carers to cope with the caring role

The relevance of the research findings to Indian context:

Applicability and equity

The evidence is drawn from high-income settings in the United Kingdom, United States and Australia; hence, applicability to the heterogenous Indian context may be uncertain. The review did not compare findings across different socio-economic groups.

Monitoring and evaluation

There is a need to monitor and evaluate the costs and cost-effectiveness of these mechanisms of support for informal caregivers within the setting of the Indian health system and society. Currently, no such data are available. The differential effects of the interventions upon different disadvantaged social groups will also need to be measured.

Policy Option 3:

Planning for hospital discharge in palliative care

Most older persons suffering from chronic disease are likely to experience frequent acute or chronic episodes requiring care within specialized units. It is desirable to reduce, where possible, demand for in-patient care through provision of acute care services at home or in the community [11]. This is a useful cost-containment measure for an under-resourced national health system by increasing efficiency of resource allocation for acute care capacity in health facilities and hospitals.

A patient's discharge from hospital may be delayed for both medical and non-medical reasons. Non-medical causes account for approximately 30% of delays and usually occur due to poor knowledge about a patient's social circumstances, deficient logistical organization, and inadequate communication between hospitals and community service providers [43]. The purpose of discharge planning is to rectify avoidable problems by developing individualized plans for patients prior to their planned departure from a hospital. Such plans typically include a pre-admission assessment, case findings on admission,

individual inpatient assessment, and discharge preparation and implementation. The discharge planning process must be monitored and documented.

Status of discharge planning

Several palliative care providers prepare detailed discharge plans for patients. These plans include evaluations of where patients can receive subsequent care closer to their home or community, where patients can procure the necessary medication, and where patients will be able to receive support when sick [44]. However, system wide and social context issues influence the effectiveness of this process such as poorer patients lacking transport money to go home, lack of 'directories' signaling the relevant health provider per geographical region or area or inadequate patient assessment by health professionals, and consequently poor or no planning for follow-up care [45].

Impact of discharge planning

A good quality systematic review by Gonçalves-Bradley DC and colleagues (2016) found that a discharge plan tailored to the individual patient probably brings about a small reduction in hospital length of stay and reduces the risk of readmission to hospital at three months follow-up for older people with a medical condition. Discharge planning may lead to increased satisfaction with healthcare for patients and professionals. There is little evidence that discharge planning reduces costs to the health service [46].

Relevance of Research Findings to Indian Context

Applicability

The review assessed studies from the United States, United Kingdom, Canada, Denmark and Australia, all high-income contexts therefore applicability is uncertain. The infrastructure for referral, health human resources capacity and community care in NHM may not be comparable to that in industrialized settings.

Equity

There was insufficient data on the differential effects of discharge planning on disadvantaged populations.

Costs and cost-effectiveness

Some studies in the review assessed the effects of the intervention on the costs of health care or the use of medication compared to usual care. The studies showed that there is little evidence that discharge planning reduces costs to the health service.

Monitoring and evaluation

The effects of discharge planning should be rigorously evaluated in the local context in India in terms of impact on patients' quality of life, on informal care givers, and on resource utilization post discharge.

Potential alternative policy interventions

Potential interventions identified by the stakeholders concerned with palliative care for older persons that have not been explicitly discussed either as policy options or implementation strategies include; gender considerations, patient empowerment, patient registration databases, training, advocacy for palliative care, pharmaceuticals management and governance [4]. Some of these are discussed further below, but for many of these the research was lacking to advise on policy direction. Advice on how to strengthen research in palliative care for older persons is also outlined.

Gender empowerment

The socio-economic empowerment of women and girls would serve to improve the lives of females generally, and not just in health. This is well recognized in the Millennium Development Goal 3 which serves to raise the literacy of women, improve shares of women in wage employment and participation in governance [47]. Because of the multi-sectoral nature of gender issues and despite the overwhelming evidence for this, interventions to empower women and girls have not been specifically discussed in this report as they are not exclusive to palliative care alone and hence would not do full justice to this problem.

Training and education for palliative care

The European School of Oncology outlines some principles to achieve palliative care education and research below [48]:

- a) Delivery of education through multi-professional programmes which emphasize the integrative approach to supporting patients
- b) Continuing professional education of all specialties and of the primary care team should teach professionals to be aware of their own limitations, to know where to access more information, and how to refer the patient to a local palliative care team
- c) There should be at least one academic centre for palliative care, with a chair of palliative medicine in the country to take the lead on medical education
- d) Information and educational programmes aimed at the public should be available in the relevant languages
- e) available in the regional languages

Research in palliative care for older persons

- a) Research in palliative care should be designed in sympathy with the needs of the patients in mind, and the methods may vary with different research questions and at different stages of the disease for older persons
- b) Methodologies for evaluating palliative care interventions and services need to be further developed and tested in older persons
- c) Funding for palliative care research in for older persons could be protected by 'ring-fencing'

d) Setting up research fellowships in palliative care studies could encourage prospective researchers in this field of care for older persons

Implementation considerations

The public health approach advocated for by the World Health Organization offers the best opportunity to incorporate the relevant policy strategies at all levels of the healthcare system for palliative care for older persons [14].

The following enablers could enhance the expansion and integration of palliative care within the mainstream health system for older persons:

- Political support from the national Ministry of Health towards private/ NGO/ charitable trust organizations in the sector
- Strong and sustained advocacy efforts by the non-state sector involving the local WHO Country office, AIDS Control program, Geriatric Society of India, and others like the civil society
- Development of national multisectoral plans and establishment of an effective multisectoral coordination mechanisms
- Establishment of cross-cluster action teams, with Ministries of Finance, Education, Planning, Social Affairs and Welfare, Trade, and Transport

It is important to understand in this context that each state have different policies and level of advancement in health care, so a homogeneous disposition would be an overambition. The health care system in India is universal. There is great discrepancy in the quality and coverage of medical treatment in India. Healthcare between states and rural and urban areas can be vastly different. Rural areas often suffer from physician shortages, and disparities between states mean that residents of the poorest states, like Bihar, often have less access to adequate healthcare than residents of relatively more affluent states. State governments provide healthcare services and health education, while the central government offers administrative and technical services. Lack of adequate coverage by the health care system in India means that many Indians turn to private healthcare providers, although this is an option generally inaccessible to the poor. To help pay for healthcare costs, insurance is available, often provided by employers, but most Indians lack health insurance, and out-of-pocket costs make up a large portion of the spending on medical treatment in India. On the other hand private hospitals in India offer world class quality health care at a fraction of the price of hospitals in developed countries. This aspect of health care in India makes it a popular destination for medical tourists. India also is a top destination for medical tourists seeking alternative treatments, such as ayurvedic medicine. India is also a popular destination for students of alternative medicine.

Barriers to integrating palliative care with care for older persons and ways to overcome them:

Recipients of care

Barriers	<p>Knowledge, competency, and care-seeking behaviour of families</p> <p>Most terminally ill patients in India prefer to be cared for at home by their families as this provides security, privacy and helps to minimize costs. But factors such as social prejudice or the stigma of illnesses such as HIV/AIDS, may result in patients and their families being socially isolated [49]. There is a widespread lack of awareness among members of the public, among policymakers, and even among health providers, about the need for palliative care services for older persons [22].</p>
Implementation strategies	<p>Home based care</p> <p>It allows patients to die with dignity at home. Members of a patient’s family, as well as their friends and neighbors are usually involved, and home-based care is suitable for traditional Indian settings. The strategy may help to minimize the costs associated with dying in hospital [50][34].</p> <p>Village health teams</p> <p>The existing Village Health Team of ASHA workers could be optimized to extend PC services [11].</p>
	<p>Vocational education</p> <p>Vocational education for informal care givers could be provided during the initial hospitalization of older persons in need palliative care. This could form part of a package of health measures to prepare family members for providing palliative care at home [34][51].</p>

Providers of care

Barriers	<p>Knowledge, competency, and attitudes of healthcare providers</p> <p>Many health providers regard palliative care as end-stage support for the dying which diverts precious time and resources away from curable conditions [52].</p>
Implementation strategies	<p>Information, education, communication</p> <p>The dissemination of educational materials, such as clinical guidelines, improves professional clinical practice.</p> <p>Educational meetings</p> <p>Continuous medical education can be provided via educational meetings or outreach visits [53].</p>

Health systems constraints

Barriers	Inadequate financial resources Most palliative care centers in the country rely on external donor funding and this makes planning difficult [54].
Implementation strategies	Sub-contracting A publicly financed health sector in which services are contracted to private providers as part of a comprehensive integrated health care program for older persons. This program would be free to recipients of palliative care [55]. Cost-sharing Cost-sharing mechanisms between providers and recipients of palliative care to offset a proportion of the financial requirements [56].

Inadequate facilities and referral processes

Barriers	Organization Diagnostic processes, referring and transferring patients present a bottleneck to effective health services. Long distances to health facilities and concerns that drugs are not available are among the most significant factors reported affecting access to health care [57].
Implementation strategies	Effective referral strategies Incorporate community volunteers, and use of structured referral sheets can help improve service delivery for palliative care for older persons, particularly in situations in which information is scarce about where to seek diagnosis and treatment for cancers [58].

Social and political constraints

Barriers	<p>Competing priorities Palliative care for older persons has not been prioritized for a separate funding plan/ investment as part of the Ministry of Health's 5 year plan [33].</p>
Implementation strategies	<p>Integration of services The integration of palliative care at all levels of service delivery within the health sector for older persons. Specific roles at each level will help to avoid additional costs (both direct and indirect) that could be incurred through the displacement of resources from priority areas by implementing palliative care as a parallel program.</p>

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Annexure1

