

Integrated pain and palliative medicine model

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Contributions: (I) Conception and design: All authors; (II) Administrative support: All authors; (III) Provision of study materials or patients: All authors; (IV) Collection and assembly of data: All authors; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

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Abstract: Pain is one of the most common, distressing and feared symptom among cancer and other patients in need of palliative care. An estimated 25% of cancer patients and 25 million people die in pain each year. Effective pain and symptom management are the core elements of palliative care which aims at reducing suffering and improving quality of life (QOL) throughout the course of illness starting from diagnosis, in sync with curative treatments and at end of life. There is a prevailing shortage of manpower apt to deal with pain and providing cost-effective palliative care and with the rise of cancer, other chronic diseases and explosion of new life-prolonging therapeutic modalities, this '*Patient-pain and palliative physician*' discrepancy is only going to increase, more so in developing countries. The need of the hour is to train all healthcare physicians and nurses especially those working in the field of chronic pain in principles of effective pain and symptom palliation, to integrate cancer pain and symptom management into existing pain management fellowships and to introduce a holistic pain and palliative care model at all levels of healthcare system. Simultaneously, of equal importance is to conduct research, evidence building and formulate policies and guidelines for meticulous symptom management among the diverse category of patients and diseases so as to have a personalized and individualistic approach to patient management. In this comprehensive review, we have pondered upon the need, advantages, barriers and recommendations to achieve ideal 'Integrated pain and palliative medicine' services, their equitable implementation and delivery to 'whomsoever in need of them'.

Keywords: Integration; pain; palliative care; medicine; cancer pain; model; pain management; intervention

Submitted Apr 03, 2016. Accepted for publication Apr 18, 2016.

doi: 10.21037/apm.2016.05.02

View this article at: <http://dx.doi.org/10.21037/apm.2016.05.02>

Introduction

Pain and symptom management are the essence of palliative care (1). Good and easily accessible pain management and palliative care are conceptually so analogous that there is a rising call to address them together. Both of them targets reduction of suffering, restoring function and improving quality of life (QOL) (2). Integrated pain and palliative medicine can therefore be a novel contribution or '*a way of dignified life and death in patients suffering from chronic and life-threatening diseases*' of healthcare system to the mankind. The purpose of this review is to ponder upon the need,

logistics, advantages, barriers and recommendations for integration of pain and palliative medicine and to propose an 'Integrated pain-palliative medicine' (IPPM) model.

The need of integrating pain and palliative medicine

Palliative care has been defined by World Health Organization (WHO) as "an approach that improves the QOL of patients (adults and children) and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of

Table 1 Prevalence of pain among chronic diseases

Disease	Pain prevalence at end of life
Heart disease	41–77% (15,16)
Chronic obstructive pulmonary disease	34–77% (11)
Kidney failure	47–50% (11)
HIV/AIDS	63–80% (11)
Liver cirrhosis	67% (17)
Multiple sclerosis	43% (18,19)
Diabetes mellitus	64% (20,21)
Rheumatoid arthritis	89% (22)
Dementias (Alzheimer's disease)	47% (23)
Parkinson's disease	82% (24,25)
Multi drug resistant tuberculosis	90% (26)

early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (2)". Worldwide 35 million people requires palliative care and with the rise of aging population, cancer and lifestyle disorders the need and the dearth of good palliative care services is only going to increase (3,4). What is required is the recognition of this need jointly by the governing and health care authorities.

Pain is often the most distressing and feared symptom (5-9). An estimated 53% and 64% of patients with cancer and advanced cancer respectively suffer from pain with more than one-third of patients having moderate-severe pain (10). An approximately 25 million patients die in pain every year (11). Cancer pain is usually multifactorial in etiology and may be due to (I) tumor itself (nerve or bone compression); (II) iatrogenic (anti-cancer treatments); (III) debility; (IV) completely different etiology (prolapsed intervertebral disc or osteoarthritis); or (V) non-physical causes (psychological distress) (12,13). Zech *et al.* found cancer pain to be somatic, visceral, neuropathic and mixed in 35%, 17%, 9% and remainder patients respectively (14). Pain is also prevalent in other chronic and life-threatening diseases (Table 1) (15,16).

These high prevalence rates define the magnitude of unrelieved pain and indicate that the adequate pain relief is not available to the majority. Adequate pain management is considered as a '*fundamental human right*' (27,28). Its importance is reflected by its recognition as the '*Fifth*

vital sign' by Joint Committee on Accreditation of Health Organizations (JCAHO) and the UN Committee on Economic, Social and Cultural Rights emphasizing that it is critical to avoid pain to allow the patients to die with dignity (2,29,30).

Pain is a bio-psychosocial phenomenon and physical, social, spiritual, economic and cognitive factors underlining the experience of total pain may act as originators of other symptoms as well (31-36). Pain has deleterious consequences on emotional health and may be associated with cognitive impairment and sleep disturbance (33,37,38). Therefore, going according to the diction "Need is the mother of all inventions"; pain and palliative medicine should be integrated and instituted with a goal of delivering co-ordinated and consistent services to those in need.

Integrating palliative care into pain training and practice

The facts justifying the integration include:

- There is a shortage of both pain and palliative care physicians in developing countries. An integrated model will ensure more manpower available to address the rising needs;
- A lot of pain physicians are already performing interventional techniques for cancer pain;
- Cancer pain and pain in cancer are not synonymous. Cancer patients do suffer from a number of non-cancer etiologies which might be better addressed by pain physician.

Need of the hour: sensitizing, educating and training the pain fellows and physicians in:

- Evidence based pain assessment and management including prescribing oral morphine;
- Comprehensive patient care;
- Principles of palliative care;
- Symptom assessment and alleviation.

The advantages of IPPM services

An integrated team approach will have far reaching consequence on strengthening the concept of 'palliative care'. Some of the stipulated and achievable advantages are:

- (I) Pain can be used both as an indicator of need as well as outcome measure of palliative care. A number of questionnaires assessing various dimensions of QOL have been devised for e.g., 'Medical Outcomes Short-Form Health Survey



Figure 1 Steps required for integration of pain and palliative medicine (IPPM).

Questionnaire 36' (SF-36), and the 'European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire' (EORTC QLQ-C30). For assessment of pain in cognitively impaired and elderly patients, special tools such as Doloplus-2 are present (39-44). Adapted tools such as the "African version of Palliative Outcome Scale" are available to be used in developing countries;

- (II) A broad multidisciplinary approach will rope in expertise with the common intention of providing a good QOL;
- (III) Early and efficient pain control in conjunction with palliative care leads to better outcomes of curative therapies and increased cancer survival (5,45);
- (IV) Optimal pain management at all stages of illness in a terminally ill patient will allow patients to live as actively as possible and avoid needless suffering.

The existing barriers retarding the establishment of IPPM

- (I) Lack of evidence based education and training opportunities: despite the growing evidence physicians and nurses still lack the basic concepts of pain assessment and management (46-50). Inadequate assessment usually results in inadequate pain management (13). Health care professionals dis-interest may be due to lack of: (i) recognition of palliative care as a specialty; (ii) evidence-based standards and guidelines; (iii) recognition both by patients and colleagues and; (iv) ignorance by private and corporate sector as they regard it as a non-profitable business. Owing to intensive efforts palliative medicine is officially certified in a number of countries like United Kingdom, Ireland, Australia, New Zealand, Taiwan, Hong Kong, Poland, Romania

and United states (51-53). It is required to follow the same in other countries as well (53).

- (II) Inadequate access to essential drugs especially opioids: not only is the access to drugs but also access to all the formulations of available drugs is inadequate. An estimated 83% of countries have low to non-existent access to opioids (54). Strict regulations on opioid prescribing, fear and misconceptions about opioid over-dosage, tolerance, addiction and diversion contributes to inadequate opioid supply and prescription (55,56). Concerns regarding altered pharmacokinetics of opioids and exaggerated pharmacodynamic effects in patients with organ dysfunction may act as hurdle in adequate opioid prescribing.
- (III) Under-reporting of symptoms due to: (i) giving less importance to symptom owing to the notion that symptoms would subside with disease control; (ii) fear of being tagged as a complaining patient; (iii) misconceptions like addiction and tolerance; and (iv) fear of effects like constipation and respiratory depression leading to 'opiophobia' (56,57).
- (IV) Problems inherent to team approach and human nature such as: (i) split responsibilities; (ii) role overlap and conflicts; (iii) duplication or fragmented efforts; (iv) promotion of superiority, seniority and groups; (v) imposition of one's perception, influencing others and claiming one modality of treatment to be superior to others; (vi) reluctance to initiate efforts, take accountabilities, share resources and manpower.
- (V) Lack of infrastructure and funding.

Recommendations-converting concept into reality! (Figure 1)

Recommendations based on evidence and expert opinion ensures quality and consistent practices. It is important

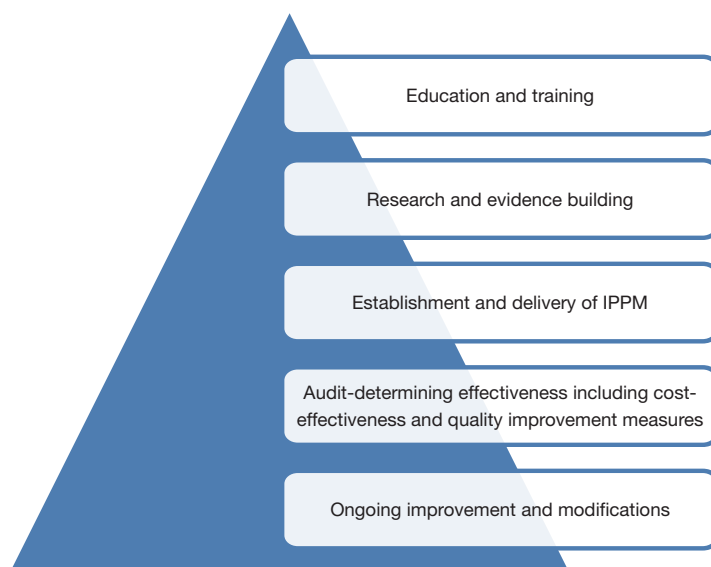


Figure 2 Building of IPPM. IPPM, integrated pain-palliative medicine.

to recognize that good pain and palliative care needs are required across different disease groups, to broaden the horizon of palliative care and to improve QOL in whomsoever patients it is required (58). A successful IPPM model should include the following (*Figure 2*).

Education, training and building manpower

Inclusion of pain and palliative care in undergraduate curriculum would enable the budding physicians to get accustomed with the key concepts such as symptom relief. Early introduction of knowledge may improve cancer pain control (59). WHO recommends inclusion of pain in ‘*courses leading to basic professional qualification*’ and multi-professional cancer pain education has been introduced by some (60,61). Development and reinforcement of evidence based curriculum like ‘European Association of Palliative Care (EAPC) undergraduate curriculum for physicians’, ‘Core Curriculum for Professional Education in Pain’ and ‘Recommendations for Nursing Practice in Pain Management’ (62,63).

- Transforming ‘*primary care physicians*’ into ‘*primary pain and palliative care physicians*’ by imparting them basic concepts of pain assessment and management including the mechanism based analgesia and the WHO analgesic ladder (*Figure 3*) (64,65).
- Creation of ‘*pain and palliative care specialist*’ with expertise in dealing complex cases and advanced

interventions. Following patients may be referred to benefit from specialized pain services (66):

- (I) VAS of ≥ 60 ;
- (II) Severe pain;
- (III) Neuropathic pain;
- (IV) Side-effects with medications provided and;
- (V) Unrelieved pain for more than 2 weeks in spite of best therapy at primary care.

- Multidisciplinary palliative care teams, in which health care providers from all specialties are trained, educated and facilitate knowledge exchange to improve competence and hence minimize substandard cancer pain treatment (67). This should include:
 - (I) Co-location of services;
 - (II) Good referral systems eliminating the need of waiting for appointments or segregated appointments on different days stretching the patient’s economic and time constraints;
 - (III) Electronic referral of cases eliminating the time draining process of procuring files, rearranging them, finding the missing links, re-referring the patient to other concerned specialties and acquainting the primary physician with the treatment changes;
 - (IV) Shared information system, care, decision making and discharge planning;
 - (V) Designation of a responsible coordinating person.
- Creation of ‘*pain and palliative care nurses*’ trained in

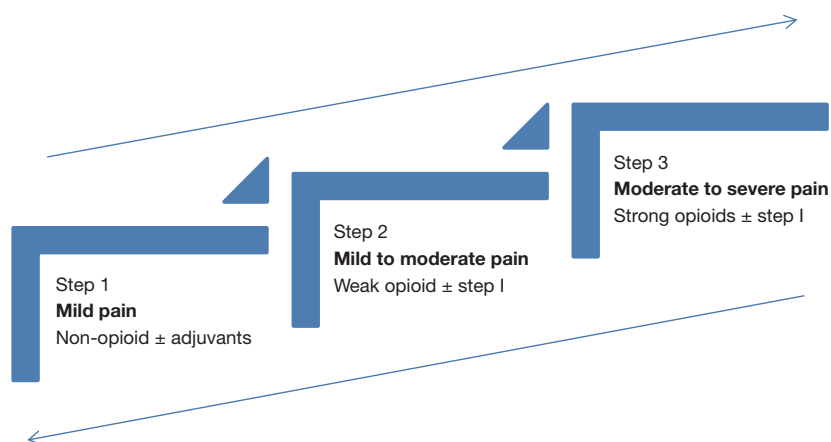


Figure 3 WHO analgesic ladder. WHO, World Health Organization.

acknowledging and managing factors contributing to ‘total pain’ and other symptoms (13). Nurses may play a pivotal role in keeping the patient pain and symptom free by early assessment and intervention (13). However inadequate assessment and imparting more strength to their own observation results in suboptimal pain management (47,68). It is required to impart core concepts like ‘pain is what and where the patient says it is’ (69), total pain, use of WHO analgesic ladder, titration of analgesics, early recognition and management of side-effects.

- Empowering social workers and caregivers by educating them about pain and other symptom recognition so that cost-effective services can be provided as close to home as possible. A number of home based palliative programs like Kaiser Permanente’s In-Home Palliative Care program and Sutter Health’s Advanced Illness Management (AIM) program are operational with the aim of home based care of patients with advanced illnesses. ‘Home based palliative care’ has been found to be associated with improved patient satisfaction; patient’s more likely to die in accordance with their wishes, reduced emergency visits, inpatient admissions and cost (70-72). The American pain society recommends healthcare professionals to educate cancer patients and their caregivers about cancer pain and its management (73).

Research and evidence building

Development and dissemination of evidence based:

- Guidelines, recommendations and algorithms for effective analgesia at all stages in terminally ill patients (17). Dr. Cicely Saunders conceptualized the pain associated with the dying process as the ‘total pain’ composed of four components: (I) physical; (II) emotional; (III) interpersonal conflicts; and (IV) nonacceptance of one’s own dying. Neglecting any of the components may result in inadequate pain relief (69,74,75);
- Adoption and adaptation of multi-dimensional and scientifically validated assessment tools like ‘Edmonton symptom assessment scale’ (ESAS), ‘Memorial symptom assessment scale’ (MSAS), ‘Needs at the end of life screening tool’ and ‘Palliative Outcome Scale’ as their use may be associated with improved patient and family outcomes (76,77). Most of the existing tools fail to address all the dimensions relevant for palliative care pain assessment (78). Trowbridge *et al.* established that use of standardized pain assessment improved pain management and reduced reported pain severity in cancer patients (79);
- Promotion of research and proper documentation to facilitate availability of data and outcome measures of IPPM services (Figure 4);
- Monitor the cost-effectiveness and impact of such integrated services on the community, patient and healthcare system to ensure consistent care (80,81);
- Neuropathic pain is found in a substantial portion of cancer patients either alone or in combination with nociceptive pain (14,82,83). Neuropathic pain is difficult to treat and requires ‘adjuvant analgesics’ (84). Not only are the physicians ignorant

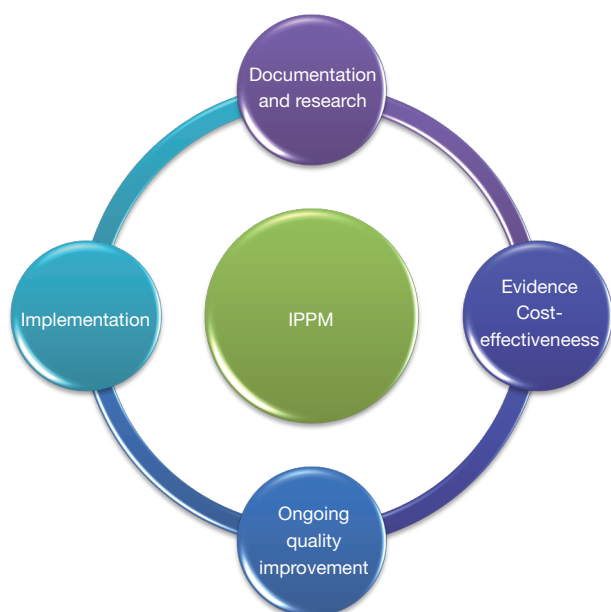


Figure 4 Ongoing research and quality improvement of IPPCS model.

of the diagnostic but also the therapeutic modalities available for neuropathic pain. Most of the guidelines for treatment of neuropathic pain including data on pharmacodynamic variables like ‘Number needed to treat’ (NNT) and ‘Number needed to harm’ (NNH) have been developed in non-cancer conditions like diabetic neuropathy and extrapolated to be used in neuropathic cancer pain (84-86). Research pertinent to prevalence, validity of different neuropathic tools in cancer pain and efficacy of adjuvants in neuropathic cancer pain is required to fill this existing gap;

- Recommendations for special groups with differing needs such as pediatric patients. About 1.2 million children suffering from congenital heart diseases, protein-energy malnutrition, meningitis, cardiovascular and other chronic diseases require palliative care (58). There is scarcity of data available on symptoms experienced by this patient group (87,88). An estimated 53–91.5% of pediatric cancer patients requiring palliative care at end of life suffer from pain (89-93). Children presents unique challenges in both assessment as well as management and are at risk of under-treatment due to (88,94-99): (I) scarcity of verbal communicators of presence, intensity and quality of pain especially in neonates and toddlers; (II) failure to identify ‘non-physical’

like psychological and social contributors to pain; (III) ‘pediatric gap’ existing in the pharmaceutical world (100-102); (IV) misconceptions that children have less sensitivity to pain (101); (V) inability to use important routes of opioid delivery such as submucosal, sublingual and patient controlled analgesia in neonates; (VI) fear of doing harm and side-effects; (VII) parent’s denial, considering pain as a sign of deterioration; (VIII) absence of expertise required to perform interventions in pediatric patients. Effective assessment and management should take developmental stage into consideration (103). The food and drug modernization act has stimulated a number of pediatric clinical studies but still few analgesic drugs are investigated in pediatric patients (88,100). Teaching physicians, nurses and guardians in identification of non-verbal indicators of pain, use of pain scales such as ‘Wong-baker faces pain rating scale’ as well as pharmacological and non-pharmacological pain management is required to tackle unrelieved pain (104).

Establishment and delivery

- A global task force to assess the feasibility, existing barrier and gaps;
- Strong inter-professional networks consisting of pain, palliative care, geriatric, family and other physicians;
- Partnership with NGO’s to deliver efficient door step palliative care;
- Integration of IPPM services into countries healthcare system as recommended by the worldwide palliative care alliance and establishment of National and regional IPPM centers (105);
- Proper allocation of global, national and state funds to ensure adequate availability of manpower, equipment and supplies;
- Easily accessible IPPM forums bringing care providers to care givers, addressing their needs and problems;
- Pain management guidelines should be integrated into institution’s palliative care program as the use of simple institutional protocol has been associated with reduced cancer pain severity (106);
- Timely institution of interventional pain procedures in severe pain where pharmacological management is ineffective or associated with side effects (107,108). It has been estimated that 10–15% of cancer patients with pain may require interventional treatments considered now

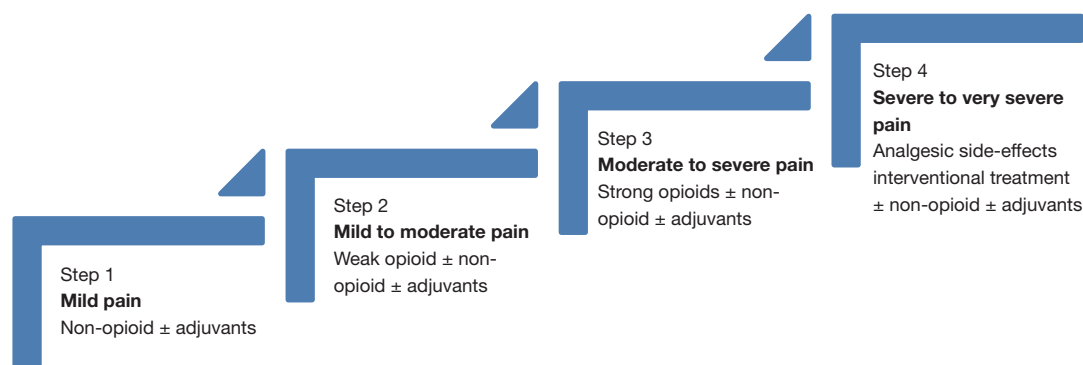


Figure 5 Modified WHO analgesic ladder. WHO, World Health Organization.

as the ‘fourth step’ of WHO analgesic ladder (*Figure 5*) (109-112). Analgesic interventions can be classified according into:

- (I) Intention of the intervention: (i) diagnostic; (ii) therapeutic;
 - (II) Nervous system targeted: (i) somatic blocks; (ii) sympathetic blocks;
 - (III) On the basis of modality used: (i) anaesthetic blocks: local anaesthetic; (ii) neurolytic blocks: chemical—alcohol, phenol, glycerol etc; thermal—conventional, pulsed and cooled radiofrequency ablation (RFA); surgical neurolysis [some of the neurolytic blocks found to be of proven value in cancer patients are: (a) neurolytic celiac plexus block (NCPB) for intractable upper abdominal visceral pain originating from structures innervated by celiac plexus (113-116); (b) superior hypogastric plexus block (SHPB) for visceral pelvic pain (110,117); (c) ganglion impar block for perineal cancer pain and radiation induced proctitis pain (118,119)]; (iii) neuromodulation: spinal cord stimulation, peripheral nerve stimulation, deep brain stimulation; (iv) neuraxial drug delivery systems: delivery of drugs like opioids, alfa 2 agonists, local anaesthetics, ziconotide and baclofen etc through epidural or intrathecal drug delivery system (111).
- Ensuring availability, rational use and inclusion of non-opioids, opioid and adjuvant analgesics into essential drugs list. Morphine and other opioid analgesics have been regarded as essential medicines by a WHO expert committee (120-122). The International Association for Hospice and Palliative Care (IAHPC) has recommended

a list of 33 essential palliative care drugs (123). Existing drug laws should be amended, if found to be overly restrictive;

- Establishment of IPPM departments in corporate and private institutions. Uniform implementation throughout the healthcare system is essential for equitable delivery. It is important to make them realize that the paying capacity of people has changed and there is a segment which needs quality services even at end of life. When this segment can spend a substantial amount on curative treatments in the hope of a cure, they will be and are eager to spend for maintenance of symptom-free and quality life as well. Recognition of the above facts have resulted in a phenomenal shift in the developed countries with more and more palliative care services being provided by for-profit organizations. Developing palliative and hospice care programs may act both as cost and quality incentive for healthcare providers and organizations (55). To be fully operational such departments should have both outpatients as well as inpatient facilities;
- Collaboration with allied organizations with the aim of conducting countrywide surveys on prevalence and establishing guidelines like the one between Indian association of palliative care and Indian society of critical care for end of life guidelines (124,125).

Essential ingredients for designing IPPM

- Review of availability of resources;
- Elimination of traditional barriers;
- Education and training of physicians, nurses and patients;
- Communication/collaboration/partnership and

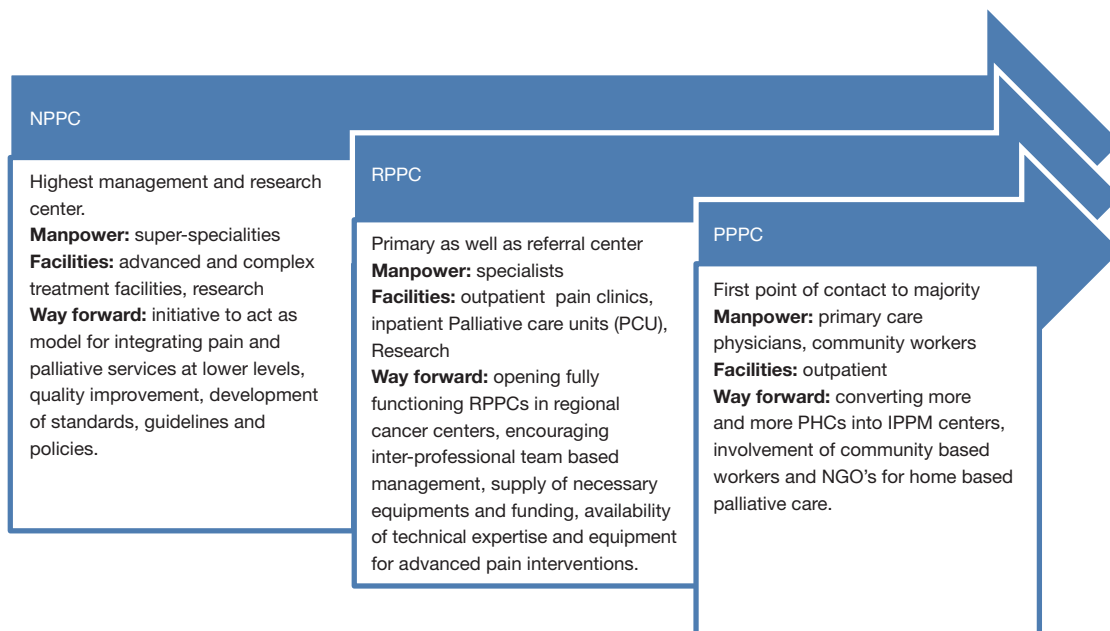


Figure 6 Organizational framework of IPPCS model.

- networking;
- Information sharing;
- Strategies adopted on the basis of prevailing needs, local health policies, economic and cultural context.

Organizational framework of IPPM model

Pain and palliative care services should be integrated at all level of healthcare system (*Figure 6*):

- (I) Primary pain and palliative care centers (PPPC): the bottom-up description emphasizes the importance of primary healthcare centers as the first access to health system to a majority of population. These centers usually operate on outpatient basis. It is importance to train the manpower at PHC in efficient, cost-effective and home-based pain and symptom management; with early referral to regional centers of complex cases;
- (II) Regional pain and palliative care centers (RPPC): these centers may act both as primary or referral centers, have both outpatient clinics and inpatient palliative care units (PCU) and are already operational (to varying extents) in regional and national cancer centers. These centers should be manned by 'inter-disciplinary palliative care teams' apt to deal with complex cases requiring

rapid opioid titration, high doses of opioids, opioid addicts and interventions. Equipment necessary for performance of above interventions like should be made available at these and higher centers. Board room discussions of complex cases and research facilities should be encouraged to ensure delivery of comprehensive and evidence based management;

- (III) National pain and palliative care centers (NPPC): these centers will act as the highest level management and research centers and should have all the super-specialties including experts in highly advanced interventions like spinal cord stimulators, intrathecal opioid device implantation in recalcitrant cases. National surveys to enumerate the prevalence of pain and palliative care requirements in various population groups should be conducted at these centers. To be successfully implemented it is important to have a hassle free referrals of difficult and recalcitrant cases from one to a higher center as every patient has the 'right to be referred' and every physician is 'obliged to refer' (72).

Above model and recommendations provide a broad base; with scope of modifications and diversification to suit different cultural, socio-economic contexts as well

support from government and various non-government organizations.

Conclusions

Pain is a global problem among chronic and terminally ill patients requiring palliative care. The physical, psychological, socioeconomic and spiritual factors underlying the total pain experience may also act as the underlying cause of other distressing symptoms. Therefore, meticulous pain management conforming to individual patient needs is of utmost importance to avoid needless suffering. Widespread dissemination of principles of cancer pain assessment, management, use of WHO analgesic ladder, employing interventional pain management in severe, recalcitrant pain with early and ego-free referral among inter-disciplinary pain and palliative care team members are required to have a multipronged approach and to curb this exponentially rising problem of 'unrelieved pain'. With the prevailing shortage of manpower apt to deal with this problem, rising trends in cancer prevalence, patients with advanced cancer living longer and in pain; it is required to educate healthcare professional in pain and other symptom management, formulate policies, standards, guidelines and evaluate their effectiveness now so that we are ready for tomorrow. To achieve an equitable delivery to those in needs, it is of vital importance to introduce IPPM services at all levels of healthcare system including corporate sector. Proper education and training to build adequate manpower apt to manage pain and other symptom, involvement of NGO's and community workers are required to ensure cost-effective '*Home and community based*' pain and palliative services'. The authors realize that it is going to be a difficult but not an invincible task.

Acknowledgements

None.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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Cite this article as: Bhatnagar S, Gupta M. Integrated pain and palliative medicine model. *Ann Palliat Med* 2016;5(3):196-208. doi: 10.21037/apm.2016.05.02