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## Issues in access to end-of-life care in low-resource areas

YOGESH JAIN, GAJANAN PHUTKE

### Abstract

Even though 1% of people require palliative and end-of-life care in low-resource situations, it remains an uncharted arena. Yet it is as important as curative care to alleviate suffering. Palliative care is not only a need in cancer and HIV disease; but is needed in a diverse group of illnesses ranging from tuberculosis, renal failures, paraplegia to chronic lung diseases. In a lower resource setting, the gaps in palliation may be the need for more technology and interventions or more healthcare professionals. Thus, palliative care will initially mean ensuring that life-prolonging treatment that most patients do not get is ensured to them. It is morally unacceptable to focus on comfort care as an alternative to advocating for patients' rights for appropriate life-prolonging treatments. If organised well and standard protocols are developed to support health workers, appropriate care can be provided for all people. Ethical principles of autonomy, non-maleficence and benevolence will have to guide this development. We will have to prioritise for high value care which means choosing cheaper alternatives that are just as effective as more expensive diagnostic or therapeutic modalities. There is a need to settle the priorities between palliative and disease-modifying or curative treatments. Major roadblocks that limit access of the rural poor to palliative care relate mainly to the misconceptions among policy-makers and physicians, large gaps in health worker training and cultural mindsets of care-providers. A specific example of misplaced policies and regulations is the poor availability of opiates, which can make end-of-life care so much more dignified in illnesses that have chronic pain or breathlessness. A three-tiered structure is proposed with a central palliative care unit which will

oversee several physicians and specially trained nurses for non-communicable diseases, who will oversee primary healthcare centre-based nurses, who in turn, will oversee village health workers.

### Introduction

Effective, affordable palliative care or end-of-life care remains unavailable to most people in rural areas (1) either because there is scarcity of physicians who are too busy pursuing curative intent or because the system has abandoned patients with no cure (2,3) leading to the prolonged agony of many.

In marginalised villages of India, one finds so many people with incurable illnesses where the health system they accessed for care has given up on them. These illnesses span different specialties from oncology to pulmonary to infectious diseases to neurological conditions. Patients often have multiple morbidities, for example:

- A patient with HIV infection with multi-drug resistant (MDR) pulmonary tuberculosis (TB) complicated by major adverse effects on the second-line MDR regimen, who has given up on drugs and is not ready to continue with the DOTS plus centre.
- A patient with post-tubercular bronchiectasis and fibrothorax with frequent chest infections, severe malnutrition, charpoy-bound, and slowly wasting away.
- Oxygen-dependent lung disease in a severely kyphoscoliotic person.
- A person with D5-D6 spinal cord injury after a motorcycle accident resulting in paraplegia and requiring chronic indwelling urinary catheter.
- A patient with lepromatous leprosy with frequent type 2 ENL reactions with limb slowly wasting away due to a non-healing trophic ulcer despite MDT for 2 years.
- A person with chronic psychosis with schizophrenia, who runs away from home, has frequent violent episodes, with exhausted family members.

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- A person with sepsis with shock, who is not improving, and wants to go home to die.
- An adult with stage 3 TB meningitis, on nasogastric feeds with no improvement after 2 months of treatment.
- A young person with bed sores, who is paraplegic due to a failed spinal surgery for a spinal injury.
- A 35-year-old person with chronic renal failure who is unable to afford maintenance haemodialysis.
- A person with cor pulmonale and right heart failure due to chronic obstructive airways disease (COAD) requiring chronic home oxygen therapy.
- A person with congenital malformations, like a pouch colon and a high anorectal malformation.
- Any number of malignancies – stage 4 cervical cancer, invasive and disfiguring oral cancer, multiple myeloma, neuroblastoma with spinal metastasis, gastric cancer with liver metastasis.

**Principles to deliver palliative care in low-resource settings**

It is well documented that palliative care and end-of-life care is as important as curative care to alleviate suffering (4). Based on our early experience with providing palliative care in low-resource settings, we have learnt the following:

1. Ethical principles of autonomy, non-maleficence and benevolence should help guide discussions between doctors and patients. It is crucial for physicians working in low-resource situations to learn when to switch from a goal of curative intent to palliative care; even though this may go against the grain of how most physicians are trained. The first reason is that physicians and nurses are trained to spend their time preferentially on those clinical situations where cure is possible. The second reason derives from the fact that medical expenditure is the major driver to impoverishment; thus patients with these illnesses should also conserve their financial, emotional and time reserves for more important palliative care rather than squander them on treatment with curative intent that are ineffective.
 

*To cure when possible, to relieve often, and to comfort always - is our motto!*
2. In resource-limited settings we should focus on high value care to evolve ways of delivering palliative care in an unjust world. In an equitable world, people in low-resource situations should receive the same standard of care as people in well-resourced situations. In an equitable world, the only treatments that should not be offered to patients are those expensive interventions with no proven additional benefit. Sometimes high value care means choosing expensive but high impact treatments (Table 1). Often high value care means choosing equally effective cheaper alternatives to expensive diagnostic or therapeutic modalities, such as using generic instead of branded drugs.

Intervention-s	High impact	Low/marginal impact
High cost	1. Anti-tuberculosis drugs for multi-drug resistant TB 2. Antiretroviral therapy 3. Cardiac surgery, valve repair/ replacement or balloon procedures 4. Renal transplant 5. Haemodialysis peritoneal dialysis for end-stage renal disease 6. Home oxygen therapy for chronic lung disease cor pulmonale	1. Erlotinib for metastatic pancreatic cancer 2. Implantable cardioverter defibrillators for cardiomyopathy 3. Tiotropium bromide for chronic obstructive pulmonary disease (COPD) 4. Long-acting, patented preparations of shorter-acting medications
Low cost	1. Oral and injectable morphine for pain 2. Oral rehydration therapy for dehydration	1. Hydrochlorothiazide for stage 1 or 2 hypertension without high-risk

It also means actively developing and using appropriate technology, like developing a cheap electrophoresis device for sickle cell diagnosis. High value care means astute and frugal use of clinical knowledge to reserve expensive technology only for decision-changing situations (5). It is important to judge technologies based on cost-impact analysis to make the highest value choices.

3. Palliative, curative or preventive medicines are not exclusive domains. Programmes that offer only one or the other do not provide optimum care and create an unjustifiable dichotomy between palliative and disease-modifying or curative treatments. In fact, the two approaches are interdependent. For example, efforts to provide palliative care to AIDS patients without simultaneous efforts to provide HIV prevention, diagnosis, and antiretroviral (ARV) treatment are never justified. The reverse is true as well. ARVs are often the most effective means of relieving the symptoms of HIV-related disease, and at the same time palliation of HIV-related symptoms and ARV side-effects can increase ARV adherence and extend life.
4. Sharing knowledge and experience with others in resource-limited settings and using information technology to obtain consultation from specialists. A WHO study in five sub-Saharan African countries found that roughly 1% of their populations is annually in need of end-of-life palliative care (7). They also concluded that because of patient preference and cost considerations, home-based palliative care was the most appropriate model. The WHO has developed a *Palliative care guideline module* as part of its package of *Interim guidelines for first-level facility health workers in low-resource settings* (8). This book covers in detail the treatment of common symptoms and we have used it as a good reference to develop our palliative care programme. Using these base guidelines, countries such as Vietnam, Uganda and Rwanda have developed excellent training materials and resource handbooks for providing

palliative care to people with cancers, HIV and other chronic illnesses.

A practical definition of palliative care is one that seeks to fill the gaps in care to make it more holistic. Thus, in a higher resource setting, there is commonly an inter-disciplinary approach with doctors, social workers, chaplains, nurses, etc, to understand patients' and families' values with advanced technology and interventions; and when appropriate, helping to shift the focus to more comfort from life-prolonging treatments. In a lower resource setting, on the other hand, we need more technology and interventions as well as more healthcare professionals for palliative care to be aligned with those goals. This is to emphasise that palliative care in a low resource setting should never mean that because resources are scarce it is morally acceptable to focus on comfort care as an alternative to advocating for patients' rights for appropriate life-prolonging treatments. Palliative care's relative inattention to disease prevention and a cautious attitude toward disease-modifying treatment, justified in resource-rich settings, is not justified in resource-limited areas where such interventions could relieve needless suffering and prevent needless death among the poor (9).

Table 2 lists life-prolonging treatments for common incurable illnesses, which should be made available in low-resource settings. This is an indicative list, to which more could be added.

**Roadblocks for palliative care in a low-resource situation**

Misconceptions among policy-makers and physicians are the major roadblocks that limit access of the rural poor to palliative care.

First, many countries or states do not have a policy on palliative or end-of-life care (10). Detractors claim that limited resources in India should be used for curative intent rather than squandered on softer skills like palliative care. As argued above, a comprehensive care model that aims to limit suffering must provide all preventive, curative and palliative care. Some also argue that palliative care is too expensive but the most effective palliative treatments are cheap. Morphine is one of the oldest off-patented drugs which is equally effective as newer drugs for pain relief (11) and is safe if well prescribed and well monitored (12). Moreover, it is important to invoke the principle of equity in delivery of important therapies to the poor. Some detractors completely abdicate their responsibility to provide palliation and argue that palliative care is not the health system's responsibility, but the responsibility of the family or of the medical social worker. This is false as physicians are the only ones who can prescribe palliative medications or recommend palliative interventions; thus a family or social worker will not be able to provide palliation alone. Furthermore, tragically some patients have no family and many public health systems do not have social workers. Another policy roadblock is lack of practices that ensure availability of palliative drugs. A specific example is of availability of opiates,

which can make end-of-life care much more dignified in illnesses that have chronic pain or breathlessness. These are unavailable due to poor policy and regulatory mechanisms (1).

Large gaps exist in health worker training so that the vast majority of health professionals have little or no knowledge of the principles and practices of palliative care (2,3). It seems that if a disease is incurable, physicians lose interest; they feel that they have nothing to offer other than to bear witness to suffering. The health system should be sensitised to consider that it is their moral duty to walk with the patient as they traverse the journey of illness, some patients cross the bridge to cure, others do not but the system must accompany the patients, it cannot abandon them in time of need.

<b>Conditions</b>	<b>Life-prolonging treatment</b>
Chronic kidney disease stage 5 in below 70 years age group	Renal replacement therapy – For older patients: both haemodialysis and peritoneal dialysis, For the young: kidney transplant
Chronic obstructive airway disease with or without cor pulmonale	Home oxygen treatment – more durable, cheaper and portable equipment
Extensive bronchiectasis	Triple inhaler therapy (beta agonist, steroid and anticholinergic)
Chronic psychosis patients who do not agree to take psychiatric treatment from distant/city clinics	Long-acting antipsychotics depot injections by health workers at home
Chronic debilitating knee or hip arthritis	Installing western toilets at their homes
Stage 4 cervical (or bladder) cancer with bilateral obstructive uropathy and renal insufficiency	Percutaneous nephrostomy
Traumatic or oncological paraplegia	Special care beds and other appliances, home care services
Severe dysphagia (severe cerebrovascular accidents, bulbar disease in some neurologic disorders, severe upper gastrointestinal strictures after corrosive ingestions)	Basic gastric tube feeds – Nasogastric or percutaneous
Spasticity – in upper motor neuron disease, spastic cerebral palsy leading to great discomfort in the affected extremity(ies)	Baclofen – is a good drug that, while not perfect, works better than benzodiazepines in the long term, is safer and can really improve quality even when curative therapy is no longer available
Refractory addiction	Narcotic replacement
Amputees after diabetic foot infections, or gangrene	Prostheses – will allow people to move around and be gainfully engaged
Advanced rectal cancer	Diverting colostomy
Painful avascular necrosis of the hips in sickle cell disease	Hip replacement or cone excision
People with permanent disability	Non-slipping walking sticks, wheelchairs and other assistive devices

Cultural barriers in opiate prescriptions are also important. A recent study found that nurses in India rarely recommended prescribing painkillers, even when they thought that the patients needed them, and doctors rarely asked whether they were needed (13). The authors of the study described it as a "culture of non-intervention". As a career choice, palliative care is not fashionable in the way a new expensive radiology study, or a complex surgical procedure, or novel therapeutic drug is (14,15). This frame of mind is unfair to the patients who just seek relief of suffering.

There are other problems at the household level. Health workers and even family members are uncomfortable with some palliative care responsibilities such as addressing toilet needs and dressing large wounds, etc.

### **Palliative care in India**

Less than 1% of India's 1.2 billion population has access to palliative care even though things have improved recently (16). The state of Kerala has the first government-led programme that provides care through Panchayati Raj institutions (PRI) based on the experience of the NGO-initiated Neighbourhood Networks in Palliative Care, though poorer states have a long way to go (17). Besides, some cancer centres in Mumbai, Bengaluru, Chennai and Ahmedabad have hospital-based programmes. There are no community-based programmes outside Kerala.

Nationally, there is a programme for palliative care (NPPC) since 2012. Even though the Narcotic Drugs and Psychotropic Substances Act has been amended in 2014, the availability of opioids is still very poor.

Palliative care is still largely meant only for cancers and in a small way for HIV. Palliative care for other major conditions such as TB, chronic kidney disease, and chronic lung disease among other illnesses has not even taken off.

The current palliative care models in India are mostly hospital-based in tertiary care cancer centres. Hospice and hospital services run by the government, private institutions and NGOs are the main palliative healthcare resources (18). A community-based model with home-based palliative care by various community persons trained and supervised by healthcare professionals is currently implemented in Kerala with the help of PRIs (17).

We must be sensitive to not just how the poor die, but also how they live before they die. In an unjust world, apparently the lives of many people in developing countries do not matter, so why should their deaths be of any concern? Is a focus on quality end-of-life care justifiable when many of the deaths in developing countries are preventable?

The issue is not palliative care versus all the injustices of the poor world. Both the lives and the deaths of people in developing countries should matter, and something should be done about both. Put another way, even if someone must die prematurely because of the injustice of global health

inequality, it is doubly unjust for that person to be condemned to an agonising death racked by preventable pain. Moreover, by focusing on improving end-of-life care, itself a significant humanitarian crisis, we may be laying the groundwork for more comprehensive, humane and ethical healthcare systems in developing countries.

### **Three tiered palliative care delivery model**

We propose a three-tiered structure with a central palliative care unit overseeing several physicians and specially trained NCD nurses who are overseeing primary healthcare centre/ community healthcare centre based nurses, who are overseeing village health workers (VHWs). Palliative care would be provided in a team where community nurses, VHWs and other health auxiliaries have a larger role.

The central palliative care unit could provide oversight, including training, monitoring, supervision and specialist consultation. It will ensure both that opioid pain medication is accessible by anyone in need while ensuring no opioids are diverted for illicit purposes. This unit may be located within teaching medical colleges/district hospitals.

At the district level, palliative care would be integrated into existing functions of physicians and specially trained NCD nurses. Physicians should perform initial evaluations of patients in need of home-based palliative care and prescribe medications, including oral morphine.

NCD nurses should monitor these patients and provide oversight to primary health centre (PHC)/community health centre (CHC) based nurses. These health centre nurses should adjust prescriptions and provide oversight to VHWs. All essential palliative care medications should be available at the health centres to maximise patient access.

At the village level, one VHW should spend the allotted time to treat patients with chronic disease. They should provide adherence support as well as palliative care for patients with chronic disease. Palliative interventions include providing clinical care and emotional support to patients throughout the course of their chronic illnesses, as well as helping to provide home-based end-of-life care for patients and their families. These VHWs can stock dressing materials and bedpans and other appliances for better end-of-life care, which could be loaned out to individual patients in their villages for finite periods until death occurs naturally, at home. This community-based work complements efforts to address palliative needs in the clinic and hospital setting and will make possible a continuum of palliative care from the hospital to the home that is essential but rarely available for marginalised communities.

*Thou shalt treat thy patients as thou wouldst thyself be treated.*

Mid-level health workers at health sub-centres should be supported with a checklist to elicit the needs of patients. This has been adapted from the African model of 2006. The same formats can also be used at the referral centres.

## End-of-life care in low-resource situations

For end-of-life care, which is a part of the continuum of care for the dying, VHWs should be supported with skills and then oversight of community nurses and senior health workers. A checklist should be followed for “How to break bad news to a family (6)”.

The community programme team should make home visits and assess the needs during end-of-life care. We have formed patient associations as peer support groups. These peer support groups also explore the non-medical needs of the family and serve as a platform for income-generating activities, besides providing a community for patients living with the same illness.

## Concluding remarks

In summary, palliative care in low-resource situations is an uncharted arena. Palliative care means ensuring life-prolonging treatment to most patients who need it. If well organised with standard protocols developed to support healthcare workers

sufficiently, appropriate palliative care can be provided for all those people who need it.

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Table 3 Symptom assessment scale in palliative care [adapted from the African Palliative Outcomes Scale (19)]	
Questions for patients:	Rating (0(nopain)–5(worst/overwhelming) 0(nopain)–5(worst/overwhelming)
Q1. Please rate your pain during the last 3 days	0–5
Q2a. Have any other symptoms (eg nausea, coughing, or constipation) been affecting how you feel in the last 3 days?	0–5
Q2b. If so, please rate each symptom during the last 3 days: Dyspnoea? Nausea or vomiting? Constipation? Diarrhoea? Others? (specify)	0–5 0–5 0–5 0–5 0 (no, not at all)–5 (overwhelmingly)
Q3. Have you been feeling worried about your illness in the past 3 days?	0–5
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0–5
Q5. Over the past 3 days, have you felt that life as worthwhile?	0–5
Q6. Over the past 3 days, have you felt at peace?	0–5
Q7. Over the past 3 days, have you had enough help and advice for your family to plan for the future?	0 (none)–5 (as much as wanted)
Questions for caregiver/supporter:	Rating
Q8. Over the past 3 days, how much information have you and your family been given?	0 (none)–5 (as much as wanted)
Q9. Over the past 3 days, how confident has the family felt caring for the patient?	0 (not at all)–5 (very confident) N/A
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all)–5 (extremely worried) N/A

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## Can the AYUSH system be instrumental in achieving universal health coverage in India?

JANMEJAYA SAMAL, RANJIT KUMAR DEHURY

### Abstract

*Universal health coverage (UHC) in the Indian context is understood as easily accessible and affordable health services for all citizens. The Planning Commission of India constituted a High Level Expert Group (HLEG) in October 2010 for the purpose of drafting the guidelines of UHC. While the primary focus of UHC is to provide financial protection to all citizens, its delivery requires an adequate health infrastructure, skilled health human resources, and access to affordable drugs and technologies so that all people receive the level and quality of care they are entitled to. This paper attempts to link the ayurveda, yoga and naturopathy, unani, siddha and homoeopathy (AYUSH) systems of medicine with UHC. Here, the AYUSH system refers to the AYUSH workforce, therapeutics and principles, and their individual role in delivering UHC to the citizens of India. In outlining the role of AYUSH, the paper lays stress on the 10 guiding principles of UHC, as proposed by the HLEG. However, as the AYUSH system is not the principal health service provider in India, the dominant system being that of allopathic medicine, a few components of UHC may not fit neatly into the AYUSH system. This paper has adopted the definition of UHC quoted by the HLEG.*

### Introduction

The High Level Expert Group (HLEG) constituted for Universal Health Coverage (UHC) by the Planning Commission of India in 2011 defines universal health coverage as “ensuring equitable access for all Indian citizens, resident in any part of the country, regardless of income level, social status, gender, caste or religion, to affordable, accountable, appropriate health services of assured quality (promotive, preventive,

curative and rehabilitative), as well as public health services addressing the wider determinants of health delivered to individuals and population, with the government being the guarantor and enabler, although not necessarily the only provider, of health and related services” (1). The HLEG report emphasises 10 guiding principles which were instrumental in framing the recommendations for the introduction of a system of UHC in India. These are as follows: (a) universality; (b) equity; (c) non-exclusion and non-discrimination; (d) comprehensive care that is rational and of good quality; (e) financial protection; (f) protection of patients’ rights such that appropriateness of care, patients’ choice, portability and continuity of care are guaranteed; (g) consolidated and strengthened public health provisioning; (h) accountability and transparency; (i) community participation; and (j) putting health in people’s hands (1). This paper attempts to appraise the role of the ayurveda, yoga and naturopathy, unani, siddha and homoeopathy (AYUSH) system in delivering UHC, and to look into the links between the above definition and guiding principles and the AYUSH workforce, therapeutics and principles.

Ayurveda, yoga and naturopathy, unani, sidha and homoeopathy are the six indigenous systems of medicine practised in India. Although homoeopathy is of German origin, the system is being practised in India together with the indigenous forms of medicine. A department called the Department of Indian System of Medicine and Homoeopathy was created in March 1995 (2,3) and renamed AYUSH in November 2003 (4). Its aim was to give greater attention to the development of these systems of medicine. Such a department was considered necessary so that these systems could have a stronger presence vis-à-vis their dominant counterpart, ie the allopathic system of medicine. This development led to an “architectural correction” in the health service, as envisaged by the National Rural Health Mission (NRHM), renamed as National Health Mission (NHM) after the addition of Urban Health Mission within its ambit. Before the introduction of the NRHM, most of the indigenous systems, including their workforces, therapeutics and principles, were limited to their own field, with a few exceptions in some states, as health is a state subjects in India. This situation was reversed after the introduction of the NRHM and the AYUSH systems were brought into the mainstream of healthcare. The NRHM, which

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