Definition & principles of palliative care
(from Latin 'palliare' = to cloak)

Palliative care and human rights
Different models of service provision
Practical examples
Important links and partners

Founders of modern palliative care

Dame Cicely Saunders
1918 - 2005

"It appears that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient’s own struggle within his compass and to bring hope and consolation to the end."

"You matter because you are you and you matter to the end of your life."

Mother Theresa
1910 - 1997

"Being unwanted, unloved, uncared for, forgotten by everybody, I think that is a much greater hunger, a much greater poverty than the person who has nothing to eat."

"I want you to be concerned about your next door neighbor. Do you know your next door neighbor?"

"Not all of us can do great things. But we can do small things with great love."

Definition & principles of palliative care

• Affirms life and regards dying as a normal process
• Neither hastens nor postpones death
• Provides relief from pain & other distressing symptoms
• Integrates the psychological & spiritual aspects of care
• Offers a support system to help patients live as actively as possible until death
• Offers a support system to help patients' families cope during the patient's illness and in their own bereavement

Components of palliative care

1. Control of pain and other symptoms
2. Psychological, spiritual and practical support
3. Support for family caregivers
4. Bereavement support
Evidence for benefits of palliative care

Strong to moderate evidence supports interventions to improve important aspects of end-of-life care.


Benefits in HIV/AIDS:
The evidence largely demonstrated that home palliative care and inpatient hospice care significantly improved patient outcomes in the domains of pain and symptom control, anxiety, insight, and spiritual wellbeing.


Benefits of palliative and hospice care teams:
Reduction in pain and other symptoms, increased satisfaction in patients and families, evidence of benefits strongest for home-based care


The scale of the problem

“Over 30 million people suffer unnecessarily from severe pain and other symptoms each year. So much is known in the management of these symptoms, but unfortunately this knowledge is not benefiting most of those in need of it. In spite of all the effort over the last two decades, the great majority of individuals with incurable diseases that need care are not getting it”


Estimated number in need in India – 60 lakh (6,000,000)


Symptoms at the end of life

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>67%</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>49%</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>27%</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>36%</td>
</tr>
<tr>
<td>Confusion</td>
<td>38%</td>
</tr>
<tr>
<td>Depression</td>
<td>38%</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>36%</td>
</tr>
<tr>
<td>Constipation</td>
<td>32%</td>
</tr>
<tr>
<td>Bedsores</td>
<td>14%</td>
</tr>
<tr>
<td>Incontinence</td>
<td>33%</td>
</tr>
</tbody>
</table>

Seale and Cartwright, 1994, The Year Before Death, Avebury, UK

What Do Patients with Serious Illnesses Want?

- Control of pain and other symptoms
- A sense of control
- Relief of burdens on the family
- Strengthen relationships with loved ones
- (Avoid inappropriate prolongation of dying)


Palliative care as a Human Right

Do you need to use HR to advance PC in your own settings?

If so:

1. Document the need
2. Document resources & knowledge regarding effectiveness of palliative care and pain management
3. Does your national/regional Department of Health know what the government has committed to as signatory nation.
4. Do government employees know what policies are required?
5. Are they concerned about sharing scarce resources equitably?
6. Can you provide a workable proposal to your government?

Brennan F and Gwyther L (2010) Advancing Palliative Care as a Human Right

Steps to promote these issues in your setting:

1. Document need & knowledge
2. Offer assistance in writing regulations/conducting cost-benefit analysis – get involved!
3. Identify Human Rights instruments and structures that can be used
4. Identify helpful regional & international resources
5. Be sensitive to relationship with Government health departments

Brennan F and Gwyther L (2010) Advancing Palliative Care as a Human Right
**Palliative care as a Human Right**

The International Covenant on Economic, Social and Cultural Rights (ICESCR): Article 12 (1) The State Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Details “core obligations” of all signatory nations, irrespective of resources.

In the context of palliative care this would oblige nations:

- To ensure a universal access to palliative care services,
- To ensure the provision of basic medications for symptom control and terminal care,
- To ensure the adoption & implementation of national pain and palliative care policies.

“Every year millions suffer horrific, avoidable pain…Palliative care needs greater attention.”

Statement made to the UN Human Rights Council by The Special Rapporteur on the Right to Health - 2008

**Meaningful Palliative Care**

“Meaningful palliative care requires a combination of socio-economic, cultural, and medical solutions. All three must be addressed. ...not purely a medical issue, the cultural and socioeconomic factors determine what kind of death we face. Today’s overemphasis on medical approaches can be balanced only by the people taking ownership”

Dr Jan Stjernsward

**Neighbourhood Network in Palliative Care in Kerala**

- Looks after more than 9000 patients at any point of time - all the services are free
- More than 10,000 community volunteers offer their services without any remuneration
- All the expenses for delivery of care (including salaries, cost of medicines, food for the family, educational support for the children) raised locally

**NNPC - Objectives**

- Empowerment of the local community to look after the bed-ridden patients in their area
- To develop a cost-effective method for the provision of palliative care

**Volunteers**

- Anyone who wants to contribute to the efforts to reduce the suffering of people living with advanced diseases
- Structured training given to those who are willing to spend at least two hours per week on the work
NNPC – Training for volunteers

- Training as part of generation and dissemination of knowledge
- 16 hours of theory
- 4 days of practical work

NNPC - structure

- Network of trained volunteers in the community
- Support system by trained professionals, institutions and organisations
- Palliative care institutions as nodal centers

Fund raising

- >98% of the total money raised locally:
  - 30% from the local government
  - 20% from Government of Kerala
  - the rest from the community
  - >75% of this as donations of less than 25 cents

A proposed system of care for chronically and incurably ill patients

- Specialists have a definite but small role
- Primary care physician in the periphery needs to be involved
- Massive involvement from the local community

Community Volunteers play the key role in NNPC

- The volunteers identify people in need of care in their area (panchayath)
- They identify the needs and plan the services that can be offered
- Seek the help of health care professionals for addressing medical and nursing issues
- Existing NNPC groups give support for initiation of these services
- As the service grows local support increases

Community action: Advantages

- Can contact hard to reach populations through informal community networks
- Tailor interventions to the needs and resources of the community
- Maximize social pressure and encourage structural changes such as policy and service reorientation
- Use local resources, knowledge, expertise
- Create conditions in which people can become empowered
- A cost effective strategy for community outreach
Government of Kerala’s Palliative Care Policy

- First government in Asia to have a palliative care policy
- Drafted in consultation with existing palliative care groups
- Emphasises community based home care
- Gives guidelines for the development of services with community participation
- Aims to integrate the existing services with mainstream health care and local Self Government institutions

Suresh Kumar 2009

National Rural Health Mission Project as the facilitator for implementing palliative care policy

- Building Awareness
  - General public
  - Health care professionals
  - LSGI members
- Capacity building
  - Health care professionals
  - General community
- Demonstration projects linked to Local Self Government Institutions
- Training centres
- Resource and Co-ordination centre

Suresh Kumar 2009

Hospice Africa Uganda

- Supplying oral morphine at home

Hospice Africa Uganda

- 200,000 AIDS victims and 22,000 cancer sufferers each year... but fewer than 250 patients yearly received palliative care during 1993–1998
- WHY? Because although 800 healthcare professionals were trained since 1993, morphine was not available

Hospice Africa Uganda

- 1993 – 1 doctor, 1 nurse and 1 driver
- 2011 – 1462 patients on the programme – mostly cared for at home, a few in hospitals - cancer and AIDS/HIV (50% combined)
  - 3 centres + 1 mobile service,
  - > 100 employees,
  - supplier of morphine to Uganda,
  - >£2m raised
  - 40% patients pay -2009-10 cost equivalent to US$ 20, Euros 12 or £13 per patient per week.
- Huge problem: care of orphans and children as caregivers
- BUT not reaching even 10% of those in need

Example from Hospice@Home in the UK

- A 97-year old lady with dementia and advanced breast cancer was in St Mary’s Hospice but was very distressed and kept asking to go home. Pain was well-controlled, her main problems were agitation and pressure sores. Her daughters, both in their 70s were not well (arthritis and respiratory problems) and lived at a distance with their husbands. They wanted her to be content but did not think they could manage her at home.
- After discussions between the family, community nurses and Hospice at Home team, she went home and her daughters cared for her, with help from these services, until she died some weeks later, peacefully and in her own bed.
Example from Hospice@Home in UK 2

37 year-old man with terminal bowel cancer, in hospital 60k from his home. At home his wife + 7-year old son +10 week old daughter. Highly symptomatic, wanted to be at home. Supported at home by his family doctor, community general nurses and the Hospice at Home team and doctors + family members.

Complex analgesia and anti-nausea medications administered via 2 continuous subcutaneous infusions (using syringe drivers), + several additional painkillers and medications for agitation. Intense nursing for pressure sores and severe constipation.

He died where he wished – and peacefully. His wife and 2 of his siblings were helped by the hospice volunteer bereavement support service. His family were lavish in their praise and appreciation of the care he received.

Public health approach in palliative care – different strategies

Top down
- Stjernsward
- Foley
- Kasa
- Bruera

Bottom up
- Stjernsward
- Kellehear
- Conway
- Kumar/ Numpeli

Public health approach in palliative care – different concepts

- “Palliative care needs to be regarded as a public health issue rather than a specialist provision for the few” (Foley)
- “Need for whole-community interventions” (Byock et al -2001)
- “Potential benefits in professionalising dying” (Sheila Payne)
- “Over medicalisation of dying” (Stjernsward)
- “Creeping medicalisation in palliative care” (Conway)

Links and partners

WHO new version of its public health model + policy recognition, drug availability and education, + implementation: i.e. development of resources, standards & business plans, + the engagement of opinion leaders.


Cross-cutting priority areas:

(1) Universal Health Care Agenda of the Philippines Department of Health; (2) achieving the UN Millennium Development Goals (MDGs) by 2015 with special focus on MDGs 4, 5 and 6 (infant health, maternal health, combat HIV/AIDS); (3) addressing the social and environmental determinants of health (MDG 7); and (4) managing health security risks and health in emergencies (MDG 8).

For the next six years, the UN’s support to the country shall focus on the following strategic priorities:
- strengthening health systems to provide equitable access to quality health care with special focus on the MDGs and priority non-communicable diseases;
- enabling individuals, families and communities to better manage their health and its determinants; and
- improving the resiliency of national and local institutions against health security risks.

Partners

Multi-stakeholders consultative meeting – Manila 2010
Low cost foundation measures important for establishing sustainable palliative care. WHO recommendations (1998/9)

**EDUCATION:**
- Public
- Healthcare professionals
- Medical and nursing students
- Postgraduate training
- Advocacy – policy makers, administrators and drug regulators

**DRUG AVAILABILITY:**
New legislation to improve availability eg low cost morphine sulphate tablets
Simplify prescribing, dispensing, distribution and administration

**GOVERNMENT POLICY**
National policy for palliative care - government policy that integrates palliative care into the healthcare system

Socio-economic cultural initiatives

"...will be as important as the medical for achieving a meaningful coverage of symptom care, bed sore prophylaxis, appropriate food and hygiene, and spiritual and existential pain"

& should be integrated with medical approaches


Funding palliative care in developing countries

**State funding** that depends on
- Political will &
- Resources

AND

Funds from non-governmental organisations, local and international, that are dependent on
- Fundraising &
- Voluntary donations from multiple sources

NGOs relevant to palliative care in India

- Open Society Institute
- International Association for Hospice and Palliative Care
- The National Hospice and Palliative Care Organisation
- International Rotary
- Grant-giving trusts and NGOs

Indian Journal of Palliative Care

Palliative Care Programmes by State: RAJASTHAN

Khalilshanker Durabji Avedna Ashram
Santoksha Durabji Memorial Hospital Campus
Bhanwari Singh Road
Jaipur - 302 015 (India)
Tel.: +91-141-2566261 (Extn: 380)
Fax : +91-141-2565565
Email: info@avedna.org
Web: www.avedna.org

Acharya Tulsi Regional Cancer Treatment & Research Institute (RCC)
Associated Group of Hospitals
S.P. Medical College
Bikaner 334 003
Tel: 540063
Contact Person: Dr. Ashok Kalwar

Palliative care provision in Rajasthan and Kerala

<table>
<thead>
<tr>
<th>Services</th>
<th>Ratio of services to population 1:1000s</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Home care</th>
<th>Day care or clinic</th>
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<tbody>
<tr>
<td>Rajasthan</td>
<td>5</td>
<td>11301</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Kerala</td>
<td>83</td>
<td>384</td>
<td>9</td>
<td>6</td>
<td>65</td>
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</table>

Barriers to palliative care in India

Some positive developments

Rajasthan, Uttar Pradesh, and Madhya Pradesh

The three poppy-growing states in India: Rajasthan, Uttar Pradesh, and Madhya Pradesh

International support for developing teams

Opioid use and narcotic regulations by state/union territory

• Poverty: huge numbers of people living in deprived conditions
• Population density
• Geography
• Opioid availability - <3% cancer patients have access to adequate pain relief
• ‘Opiophobia’ within the medical profession
• Workforce development
• Limited national palliative care policy
• Marginalisation of palliative care within the medical establishment
• Lack of state funding for health or social security

• Projects: WHO, Indian Association of Palliative Care and the Government of India (GOI)
• ‘GOI will include palliative care in the National Cancer Control Program for the country’s next five year plan, starting in April 2007: improved opioid availability, palliative care education, and service development’ (restricted to cancer sufferers) (Kapoor S, Joshi D. 2009) India: Opioid availability - an update. J Pain Symptom Manage 37(Suppl. 2):186-198.
• Growing public and medical acceptance of palliative care
• Increasing volunteers
• Partnerships with international agencies eg International Association for Hospice & Palliative Care
• Growing ‘grassroots’ awareness and demand
• ‘A public health strategy, (eg WHO), offers the best approach for translating knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in need of palliative care in developing countries.’

Hailey Hospice, Sydney, Australia set up Home Based Care project 2003-2008 in southern Africa to address WHO/HIV/AIDS efforts (see S. Africa, Botswana, Mozambique). WHO project partner was Hospice Africa Network for Palliative Care in Africa. Collaborating Center at the University of Cape Town. Part of the WHO project partnership to improve availability of and access to opioid analgesics; (Paing and Policy Studies Group/RWHO). Collaborating Center at the University of Wisconsin Comprehensive Cancer Center (The Pain and Palliative Care Society (PPCS) (Calcutta, Kerkat)). The Indian Association of Palliative Care (IAPC) (New Delhi, India) - national palliative care association. Several national and state palliative care societies have been formed. Several state government ministries of health and education have been making oral morphine solution since the 1990s, and the Regional Cancer Centre at Trivandrum (Kerala, India) and the Regional Cancer Center at Bangalore (S. India) have also started making oral morphine capsules in May 2007 (5 and 10 mg). In collaboration with the College of Pharmaceutical Sciences which is in the same campus. A 10 mg morphine capsule costs Rs 7.00.

The Palliative Care Toolkit Trainer’s Manual
• http://www.yellowdog.co.uk/palcare/index.php?name=palcareradio/19478
• The Palliative Care Toolkit and The Palliative Care Toolkit Teacher’s Manual produced by Help the Hospices are widely used as aids in mentoring. (www.helpthehospices.org.uk/internationally/educationand-training/palliative-care-toolkit/)
• Mentoring for doctors: Signposts to current practice for career grade doctors, of charge by calling +44(0)2075208222 or through the website (www.helpthehospices.org.uk/)


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Lack of access to essential medicines, including for pain relief, is a global human rights issue & must be addressed forcefully….


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UN Special Rapporteur on Torture, Cruel and Inhuman Treatment, 2008

Palliative care progress in India

India, as far as the palliative care movement is concerned, is perhaps the most successful example of ‘going native’ and integration with cultural norms. Cautionary tale as the project collapsed when the lead diocese project coordinator had to leave her post.

The Palliative Care Movement in India: Another Freedom Struggle or a Silent Revolution?

...most of the problems of advanced diseases are ‘non-medical’ in nature, in that the community has a role to play. Thus the ‘third sector’ or ‘civil society’, a fellowship of individuals ‘arrived’ (and continues to do so) at an arena of ‘uncensored collective action around shared interests’ with its lakshman rekha (‘protective boundary’, ‘boundary line’) drawn between the other players – the State, Family or Commercial interests


Opioid availability by state is ‘multiple, complex and entrenched’

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Thank you for your attention

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