

Palliative care in India

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Palliative care

- Origin – Pallium
- Hospice – last millenium – place of rest for travelleres or pilgrims.
- Palliative care – improves QOL in terminally ill patients to relieve suffering (not cure)
- Physical, economical, psychological, and social aspects

Palliative care

- Avoid aggressive futile care at end of life
- Respite programmes
- Assists in end of life with dignity
- Help family cope with loss and grief during illness and bereavement

Indications

- Mainly cancer
- Also HIV
- Other chronic/terminal illnesses e.g. Lung, renal, heart, neurological diseases

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

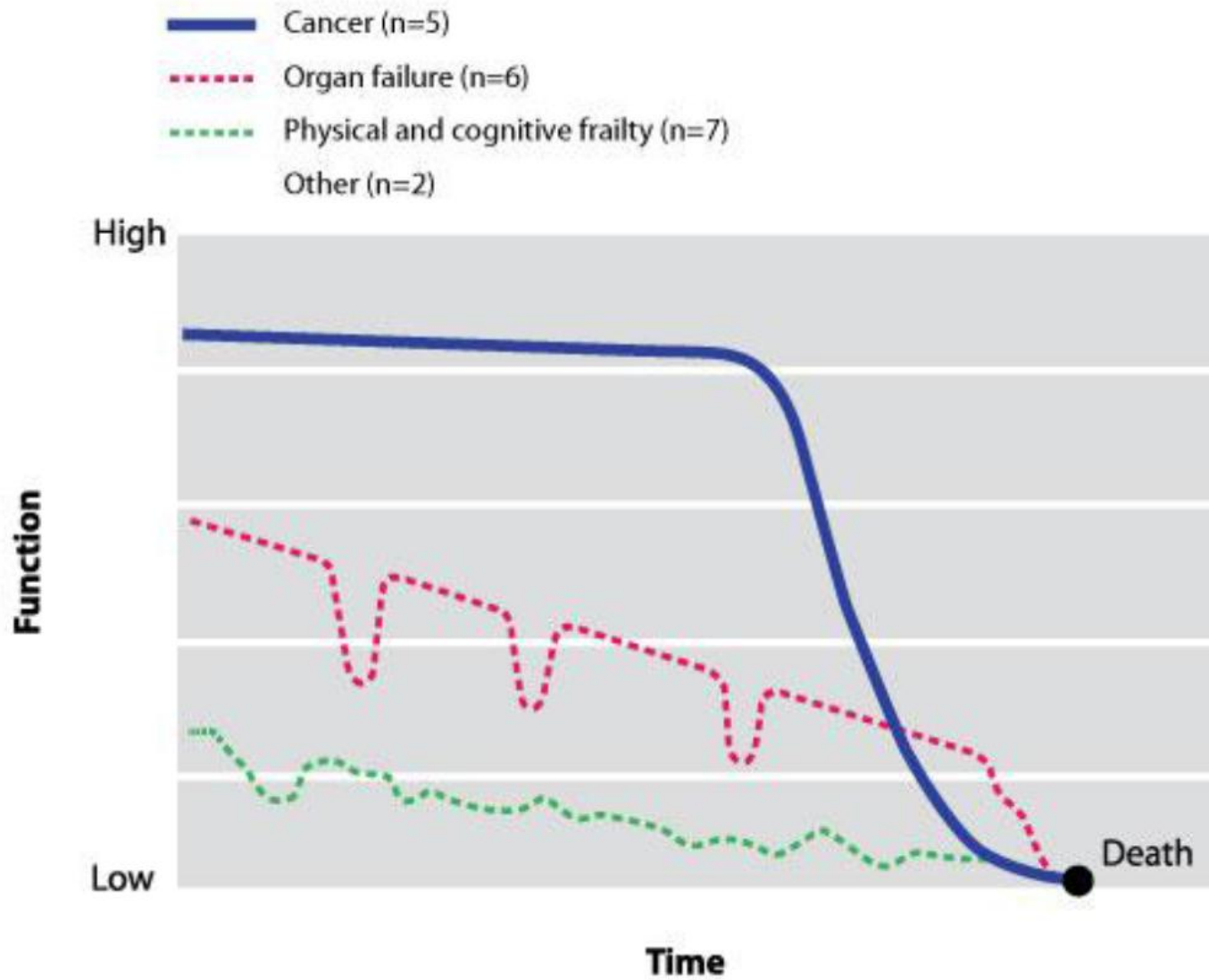


Figure 1. Trajectories of illness at end of life (Murray et al)²

Symptoms

- Pain
- Fatigue
- Nausea
- Constipation
- Loss of appetite
- Dyspnoea
- Insomnia
- Depression

- Pain management
- Symptom management
- Emotional support
- Honest
- Pressure sores, personal hygiene, nutrition
- Protect against abandonment and isolation

EVOLVING MODEL OF PALLIATIVE CARE

**“Active
Treatment”**

**Palliative
Care**

**D
E
A
T
H**

**Cure/Life-prolonging
Intent**

**Palliative/
Comfort Intent**

**D
E
A
T
H**

Bereavement

Palliative care worldwide

- 1967 – first hospice in UK
- 1987 – palliative medicine recognised as a speciality

Palliative care in India

- India ranks low in the Quality of Death Index.
- The Quality of Death Index from Singapore, measures the quality of Palliative Care in 80 countries around the world.
- Uses 20 quantitative and qualitative indicators across five categories:
 - the Palliative and Healthcare environment
 - human resources
 - affordability of care
 - quality of care
 - level of community engagement.
- UK – ranks 1, US ranks 9th; India ranks 67th .
- Kerala contributes to 2/3 of India's Palliative care services, being the home of only 3% of India's population.

WORLD MAP



India

- 7th largest country
- Population 1.3 billion
- 1 million new cancer cases every year
- Health care unregulated
- < 1% access to pain relief & palliative care
(~900 centres)

India

- Mainly as out-patient home care with family members as care providers
- A lot needs to improve
- NGO charitable organisations
- Involve community
- Pain and palliative care society

Milestones

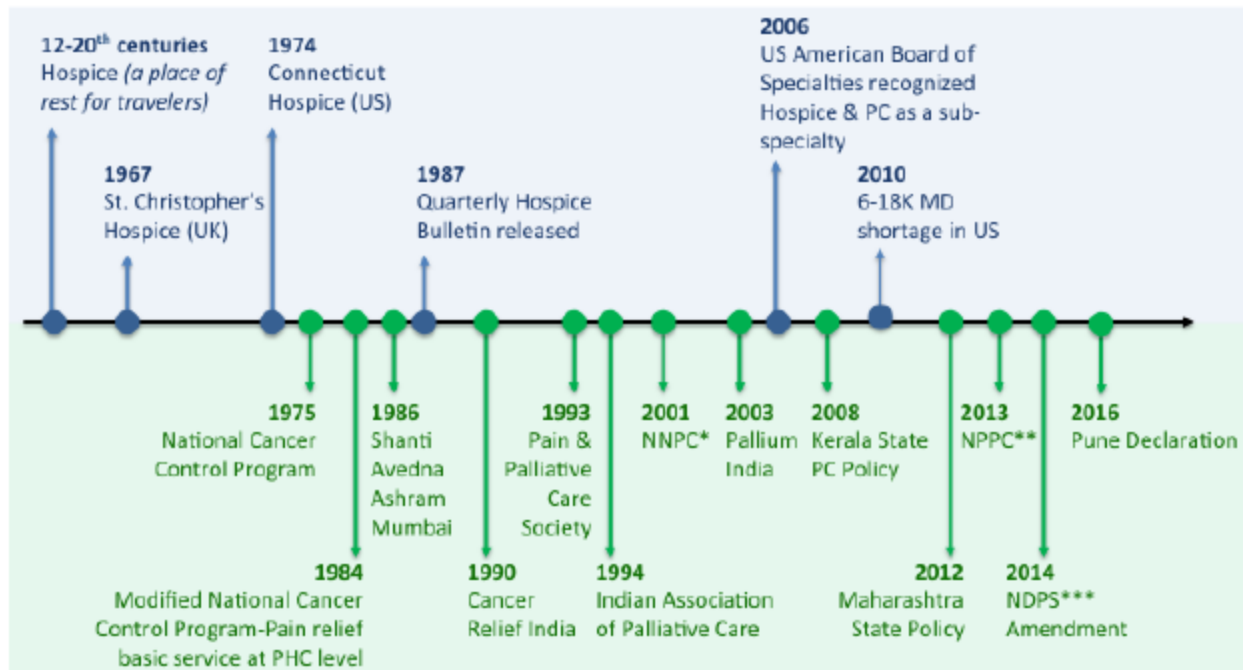
- 1986 – first hospice India
- 1990 – Cancer Relief India (CRI) – a UK charity
- 1993 – 95 CRI & Cancer Relief Macmillan fund with WHO facilitate training of nurses and doctors
- 1994 – pain and palliative clinic at Calicut
- 1997 – Can Support, New Delhi – first palliative care home in North India

Milestones

- 1999 – first nurse from India sponsored by CRI to complete the diploma in palliative nursing in Oxford Brookes University
- Neighbourhood Network in Palliative Care (NNPC)
- Indian association of palliative care (WHO and Govt. Of India)
- 2012 – National programme for palliative care (NPCC)
- 2014 – law overcoming legal barriers to opiod access
- 135 palliative care hospitals and care homes across 16 states (out of 29)

Milestones

- Pallium – started in 2014, new palliative care information centre
- TIPS – WHO collaborating centre for training and policy for access to pain relief
- EPEC (Education in palliative and end of life care)– INDIA



Timeline: Development of Palliative Care

International
India

*Neighborhood Network in Palliative Care
**National Program in Palliative Care
***Narcotic Drugs & Psychotropic Substances Act

Figure 2. Timeline of Palliative Care development

Cultural considerations

- Literacy rate 74% (average)
- Culturally diverse
 - 79.8% Hinduism
 - 14.2% Islam
 - 2.3% Christianity
 - 1.7% Sikhism
 - 0.7% Buddhism
 - 0.4% Jainism
 - 0.9% others
- Death - taboo subject
- Afterlife

Summary

- Embrace a holistic approach
- Create an environment which nurtures physical, emotional and social wellbeing of the individual
- Death is a normal part of life
- Euthanasia
- Team work
- Confidentiality

Thank you