Sustainable Palliative Care Projects in India

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National Coordinator
Palliative Care Programme of
The Christian Medical Association of India (CMAI)
“How people die remains in the memory of those who live on”

Dame Cicely Saunders
Plan

• Important developments in PC in India
• Strengths
• Weakness / barriers
• Few examples of effective projects
  - Karunashraya (Hospice)
  - NNPC (Community)
  - CanSupport (Home Care)
  - BBH (Fully integrated)
• Challenges / opportunities / solutions
• Take home message
Important Developments

a) Indian Association of Palliative Care (1994)
b) Change in Narcotic laws / Morphine availability
c) Education & Training
d) Community involvement
e) Policy – State Policy
f) National Strategic plan
g) Overseas support WHO / UK / USA / Australia
h) Indian Journal of Palliative Care
i) Important networking & Collaborations
QUALITY OF DEATH INDEX

Overall rank 40/40

Basic EOL HC environment 39/40

Quality of EOLC 37/40

Availability of EOLC 35/40

Cost of EOLC 39/40

INDIA
Strengths

1. Family involvement
2. Faith
3. Help through overseas friends
4. WHO involvement
5. Morphine availability
6. Community involvement
7. State level Policy
8. Variety of education programmes
9. IAPC & ISCCM joining hands
10. Network of Mission Hospitals serving the poor eg- CMAI, EHA, EMFI, & CHAI
Weakness

1. Funding
2. Resources
3. No National Policy yet for palliative care
4. Still mostly Cancer oriented
5. Limited integration
6. Not in undergraduate medical curriculum
7. Limited awareness in professionals
8. Not enough trained HCAs
9. Limited public awareness
10. No Laws for withholding or withdrawing Life Support.
11. Health Care Service has become Health Care Industry
Karunashraya – Bengaluru

Info by Dr Nagesh Simha Med Director

• 50 bed hospice for cancer patients
• Serves mainly Cancer patients
• Service totally free
• 80% by local donations
• 20% by HANS Foundation, USA
• Other overseas support – CISCO, Global Giving
• Local fund raising – 20%
• Cost per bed/day – Rs 2000/-
• Cost per home visit – Rs 1500/-
• No support from state Govt
• Sustainable with continued funding
CanSupport
(Info by Dr Ambika Rajvanshi CEO)

• CanSupport, founded by Mrs Harmala Gupta in 1996, is the largest home-based palliative care programme in India.
• Six bases / 13 teams
• Networking with IRCH
• Volunteers
• Training
• Day care
• Help line
• Equipment / medication support
• Bereavement and rehab services for family
CanSupport

• 80% funds through local donations
• 20% Overseas funding
• 15% through investments
• Services totally free of charge
• Aimed mainly at the less privileged.
• No support from State Govt
NNPC – Kerala
Info by Dr Anil Paleri - CEO

• It is a concept for engaging the community in palliative care.
• 50% coverage (National <2%)
• All people needing PC + Long Term Care & Rehab
• Around 260 community care centres
• Care is totally free of charge
• Funds locally generated – micro-donations
• Donations through CSR of companies, Expats
• No financial support directly from Govt.
• Govt funded PHC and LSGI - close links to NNPC
• Concept a social movement and can sustain
BBH – Integrated model

• Fully integrated into services of a Mission Hosp
• For Cancer and all non-cancer patients
• OP clinics
• IP care – no separate ward
• Home care - Urban team & rural team
• Multidisciplinary multipronged approach
• 24 x 7 advisory support on phone
• Bereavement Support
• Training
• Volunteers involvement
• 60% deaths at home managed by family
• High quality but low coverage.
BBH – Integrated model

• 60% of expenses met by Endowment interest
• 40% by local donations
• Cost per visit Rs1600/-
• No overseas support for urban programme other than Grant of Rs7500000/- received 1998
• Grant of Rs2700000/- for first year of rural programme.
• No support from State Govt
• Expansion of Urban programme may need charging for services and consumables.
Our vision!

Restoring wholeness in people with life limiting illness in the spirit of CHRIST
Our Emblem

• Emblem shows flower and pod of Opium poppy

• Morphine in olden days known as – ‘GOM’ - God’s own medicine!

• (Pod) Appearance of chalice with cross represents CHRIST – God’s own gift for healing and wholeness!

• Yellow rays of hope
  “I came that they may have life” – abundant life now and eternal life hereafter!

• Green leaves – also a sign of new life!
BBH model of palliative care - An integrated approach!

Base Mission Hospital + Multi Disc PCT

IP - Symptom control
- Terminal care
- Respite care

OP - Combined-
- pall / onc cl
- support groups

Home care
Multi-disc
Multi-pronged
+ continuity of care

<25kms
Day care / procedures

>25kms
Local GP/hosp
Remote supervised - care

Bereavement support
Ca prev / behav change
All set and ready to go!
Yes, its good to go as a team!
Family driver!
Equipment required

10ml syringe, 23 – 25 g butterfly needle with cannula
ampules, ampule cutter, spirit swabs, plaster roll
Comfortable and happy at home – few days before death
Empowered!
Sedated & comfortable, able to sleep in his mother’s lap
Nurses checking bowel sounds
Team work to complete various tasks
Filling a waterbed can be a challenge in the village
Wheelchairs can go a long way!
Homes can be very small
Family Conference
Rarely a paracentesis at home
Praying with permission of pt and family
Home made sterile vaseline gauze and powdered metronidazole tablets
Memorial Service – lighting a candle in memory of the loved one
Our poster won the ‘Best Poster’ award at the 14th International IAPC conference at TATA Memorial Hospital, Mumbai in Feb ‘07.

Feedback by families on Palliative Home Care Service
provided by Bangalore Baptist Hospital

Macedon S.C., Vinoda D, Sujatha P, Arvind I

Introduction
In India, provision of palliative care services remains low and the coverage is fragmented (1). The quality of care also needs evaluation by audit and feedback from users of the service. This is essential to maintain quality of service and also to make improvements as needed.

It is difficult to conduct clinical audit using direct feedback from dying patients. They are usually too ill to respond to even simple questions. Families are often too distressed while the patient is dying. Information about service utilization and the effectiveness of terminal care can be obtained from relatives after patients have died (2).

The Bangalore Baptist Hospital started its palliative care service in 1995 and palliative home care was added in 1996. Feedback on our palliative home care service was obtained through a questionnaire given to families after the death of their loved one. A total of 100 responses were analyzed and presented.

Method
A questionnaire was devised to cover all aspects of the palliative home care service provided. After each question space was also provided for any additional comments. 100 such responses over a three-year period are analyzed and presented. A sample questionnaire is shown in this presentation.

All set and ready to go

Sample questionnaire

Family conference

Teaching wife to give SC injections

Feedback of 100 responses

1. What is your opinion about the care your patient received? Good = 50 Poor = 5
2. Communication Good = 73 Poor = 27
3. Availability of home supplies Good = 50 Poor = 50
4. Home support Good = 5 rough = 2
5. Home support and other parameters Good = 50 Poor = 50
6. Medication and other parameters Good = 50 Poor = 50
7. How often was the patient visited? Daily = 72 Every 2 days = 12 Every 3 days = 12 Not reported = 4
8. Relief from pain was achieved? Yes = 81 Not achieved = 19
9. How long were relief from pain achieved? 0-1 day = 7 1-7 days = 15 >7 days = 2 Not reported = 1
10. The patient is comfortable? Yes = 81 Not comfortable = 19

Conclusion: We are grateful to all the families who responded by giving their feedback. We are very encouraged by all their appreciation and constructive comments. Based on their inputs we have taken steps to improve the services as and when they were needed. There is need for a standard audit tool to evaluate the quality of palliative care services in the country. Similarly a standard feedback form by family could also be used by all palliative care services in the country. This will help to maintain and improve quality by a uniform evaluation approach. We hope our attempts through this presentation will facilitate this process of audit and evaluation.

Bibliography: (1) International Observatory on End of Life Care, Country Report-India 2006. (2) National Council for Hospice and Specialist Palliative Care Services - Changing Care—Guidelines for managing the last days of life in adults, Dec 2001.
Project ‘EPHATHA’ (Be opened) 
KM Church volunteer’s training 

Koramangala Methodist Church
NFPM - Faculty meeting
A state-of-the-art Linear accelerator RT facility
By continued support from Wake Forest University, Winston-Salem, NC, USA

A spin-off of Palliative Care!
Kurian Foundation Grant
Rural PC project (200 / 500)
The continuum of palliative care

Modified from -
http://depts.washington.edu/pallcare/training/ppt.shtml

Therapies to modify disease
*(curative, restorative intent)*

Life Closure

Actively Dying

Preventive care
Healthy life style

Therapies to relieve suffering
improve quality of life

1yr - 6m

Diagnosis

Palliative Care

WHO

GSF

NICE

GMC

EOLC

IICP

Death

Bereavement Care

GSF – Gold Standards Framework
IICP – Indian Integrated Care Pathway

NICE – National Institute for Clinical Exc
GMC – General Medical Council
Joining hands!
IAPC & ISCCM
Position Paper

End of Life Care Policy for the Dying: Consensus Position Statement of Indian Association of Palliative Care

Stanley C Macaden, Naveen Salins¹, Maryann Muckaden¹, Priyadarshini Kulkarni², Anjum Joad³, Vivek Nirabhawane⁴, Srinagesh Simha⁵
End-of-life care policy: An integrated care plan for the dying

A Joint Position Statement of the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC)
Sheila Nainan Myatra, Naveen Salins¹, Shivakumar Iyer², Stanley C. Macaden³, Jigeeshu V. Divatia, Maryann Muckaden¹, Priyadarshini Kulkarni⁴, Srinagesh Simha⁵, Raj Kumar Mani⁶
End of Life Care Certificate Program

Organised by:
Tata Memorial Hospital,
Indian Society of Critical Care Medicine and
Indian Association of Palliative Care

Venue: Choksi Auditorium, Tata Memorial Hospital, Mumbai.
Date and Time: 11th October 2014, 9am to 1pm

Theme:
Millions of Indians die in pain and needless suffering. Who cares? We do!!

Program structure:

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<td>09.15</td>
<td>Introduction to EOLC: Padma Bushan Prof B. M. Hegde</td>
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<td>Retired Vice-Chancellor, Manipal University</td>
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<td>EOLC symptom management: Dr. Prince John</td>
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<td>Palliative Medicine Consultant, Asian Institute of Oncology, Mumbai</td>
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<td>10.15</td>
<td>Process and pathway of EOLC: Dr. Vijaya Patil</td>
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<td>EOLC Communication: Dr. Naveen Salins</td>
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<td>11.45</td>
<td>Consultant, Department of Palliative Medicine, Tata Memorial Hospital</td>
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<td>11.45</td>
<td>Ethics and Legal aspects of EOLC: Dr. Farad Kapadia</td>
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Program Co-ordinators
Dr. Sheila Myatra and Dr. Naveen Salins

For registration contact:
Dr. Seema Rao
Mobile: 9892336650
Email: eolc.education.tmc@gmail.com

(Registration is free. Register early and confirm participation as we have limited seating capacity. Last day for registration is October 7, 2014. No spot registrations)
Libby Salnow with BBH Team
Indian adaptation of LCP
Enabling death with dignity
5 – day workshop by CMAI – April

Supported by Humanitarian Fund of BMA and RCN (UK)
LCP - International Activity

- Argentina
- Australia
- China
- Germany
- Holland
- India
- Italy
- Japan
- Malaysia
- New Zealand
- Norway
- Slovenia
- Spain
- Sweden
- Switzerland
First Foundation Course at BBH – Jan 11th-13th 2016

International Collaborative for Best Care for the Dying Person
Challenges / Solutions

1. PC in all Health related undergraduate curricula
2. Mandatory EOLC-D certification for Drs /Nurses
3. +/- IAPC certificate course in Palliative Care
4. More integration / networking
5. Balance between coverage & quality
6. Auditing of services by NABH
7. Army of volunteers
8. Army of HCAs
9. More media involvement to create public awareness
10. Partnerships + Stewardship
11. Empowerment of family
12. Community health approach – WHO
   (Acceptable, Appropriate, Available, Accessible, Affordable)
14. National Policy / State Policy
15. Appropriate Legal support through Legislation
16. Multi centre research – balance between quantitative & qualitative research
Tripartite Partnership & Stewardship

Health Care Set Up

Person & Family Empowerment To Harness Potential

National Body

Community

Facilitator
Take home message

• Palliative home care helps people to die at home peacefully
• Empowering the family is key
• Involvement of volunteers helps effectiveness
• Balance between coverage & quality impt
• The subcutaneous route must be ‘exploited’!
• The ‘Family driver’ is efficient!
• Partnership + Stewardship = Success
• Preventing financial ruin of family paramount
Two roads diverged in a wood,
and I took the one less travelled by,
and that has made all the difference.

- Robert Frost
“You are the salt of the earth
You are the light of the world”

Make a difference
By the pathway of
LOVE & GRACE
Truth & Life

Leading to
Wholeness and Healing in JESUS.
Thank You
Important Issues for Sustainability

- Concept of palliative care
- Advocacy
- Awareness / education
- Resources
- Service delivery / person centred / Community Health approach
- Balance between quality & coverage / avoid too much specialisation
- Empowerment of Family & Community (volunteers)
- Financial
- Integration / Networking / Collaboration
- Partnership & Stewardship
- Resilience and spirit of restoration (Faith based / Humanity)
- Research – balance between quantitative and qualitative research