Sustainable Palliative Care Projects in India

Dr Stanley C. Macaden
National Coordinator
Palliative Care Programme of
The Christian Medical Association of India (CMAI)

PCW Conf B'ham 26/27 Sept '15

Entrance to BBH

"How people die remains in the memory of those who live on"

Dame Cicely Saunders

From National Geographic

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


Kabul
Rawalpindi
Lahore
Jaipur
New Delhi
(Nepal)
Bhutan
Lucknow
Ahmedabad
India
(Bangladesh)
Kolkata
Mumbai
A
Pune
Hyderabad
Bay of
Bengal
Bangalore
Chennai
Kerala

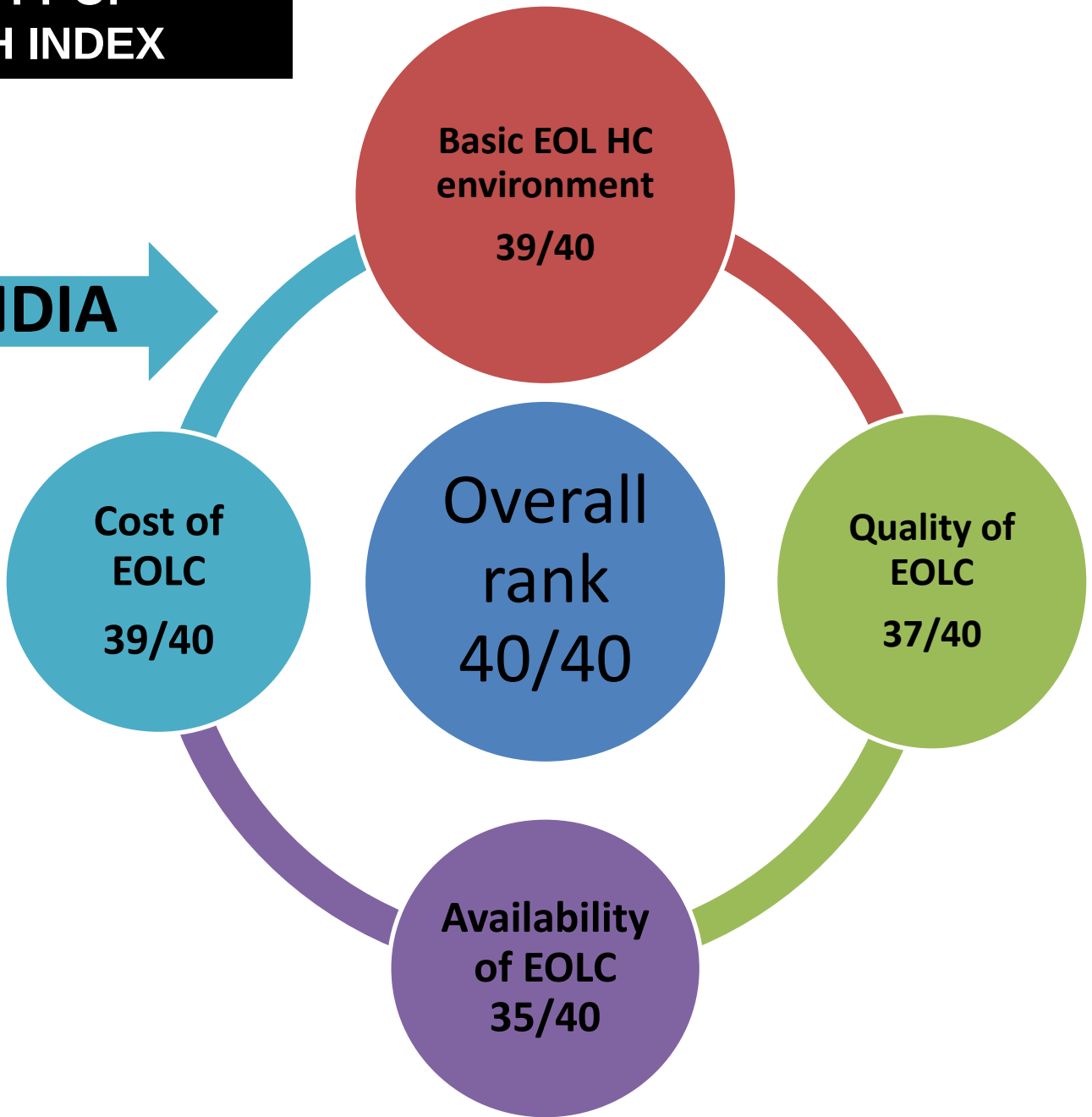
Important Developments

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

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 cetres
- 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.

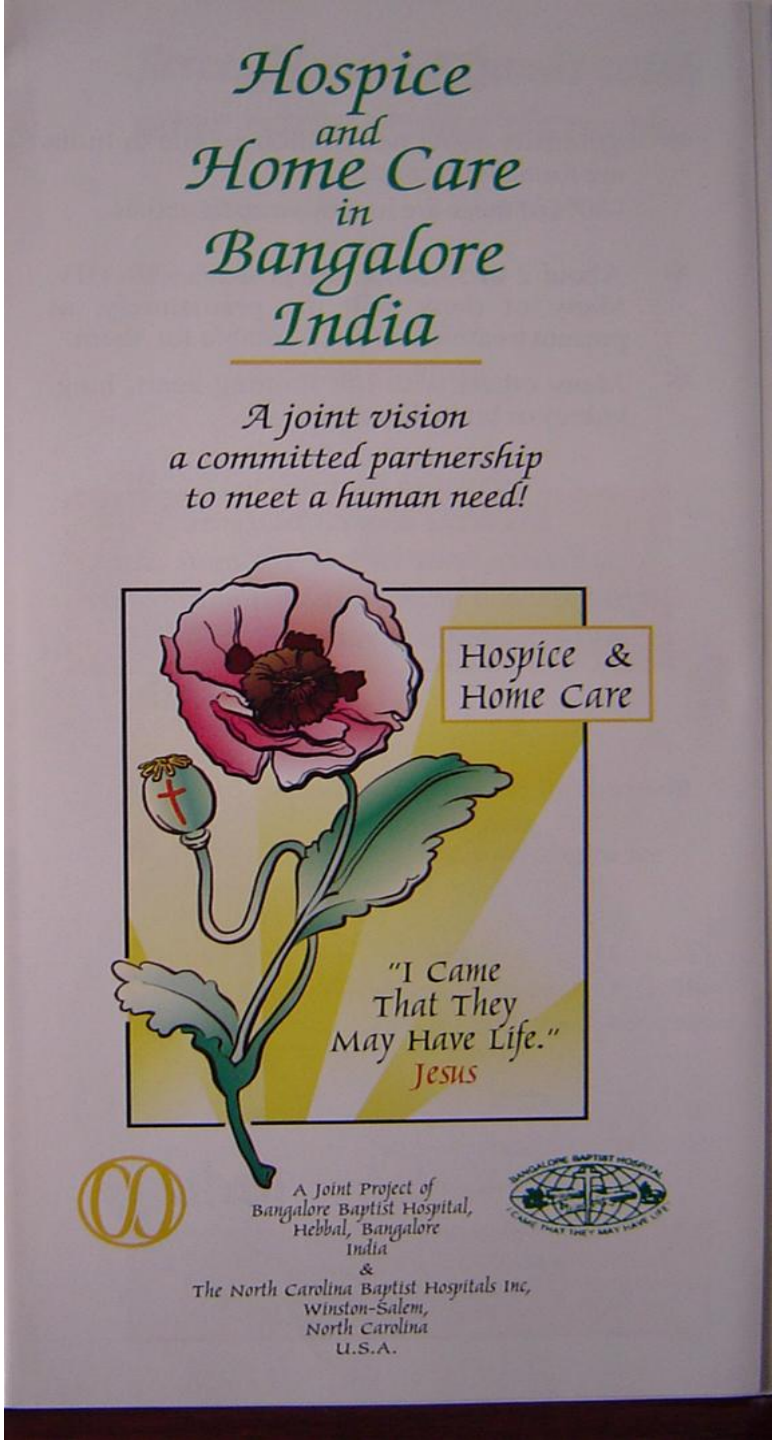
Our vision !

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

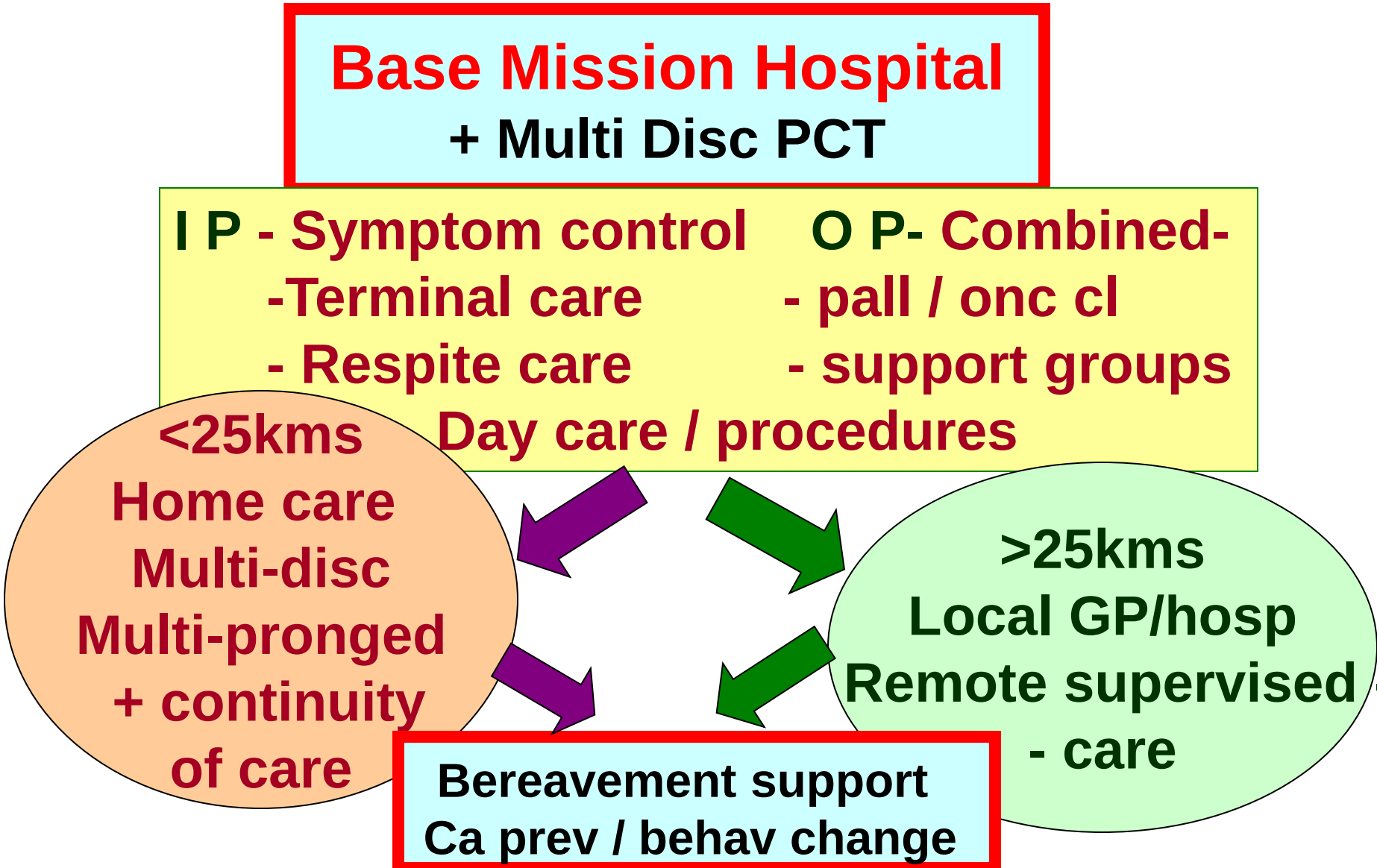
Our Emblem

- 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 !

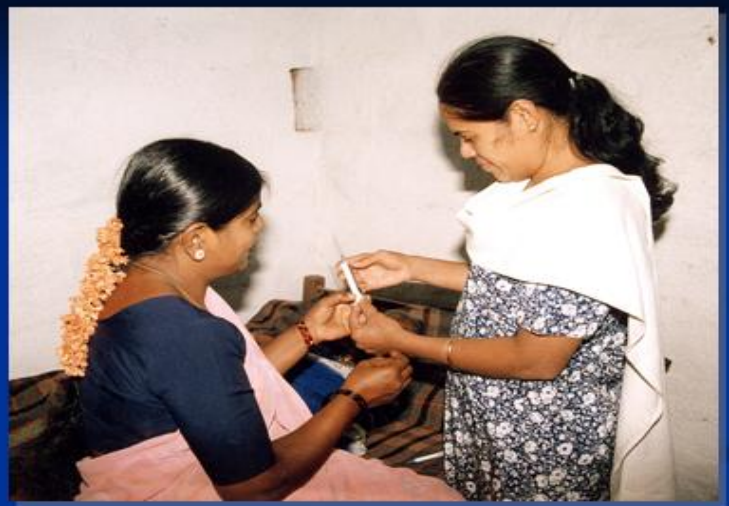


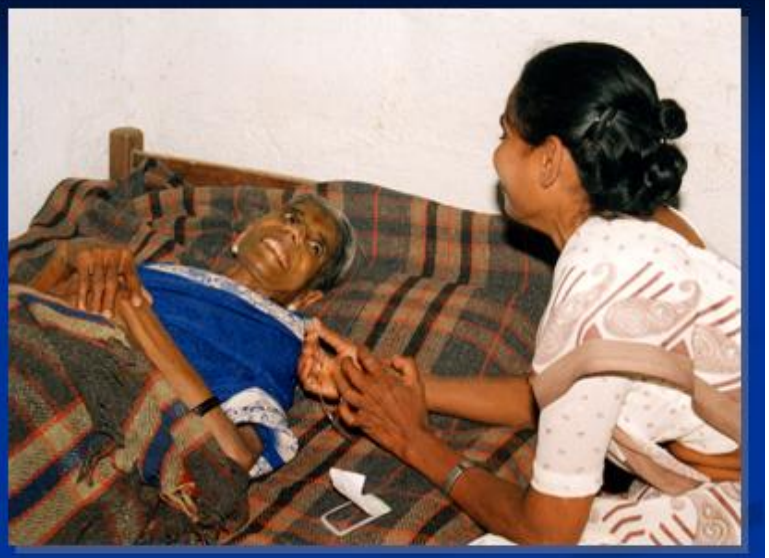
All set and ready to go!

Yes, its good to go as a team!

Family driver!!

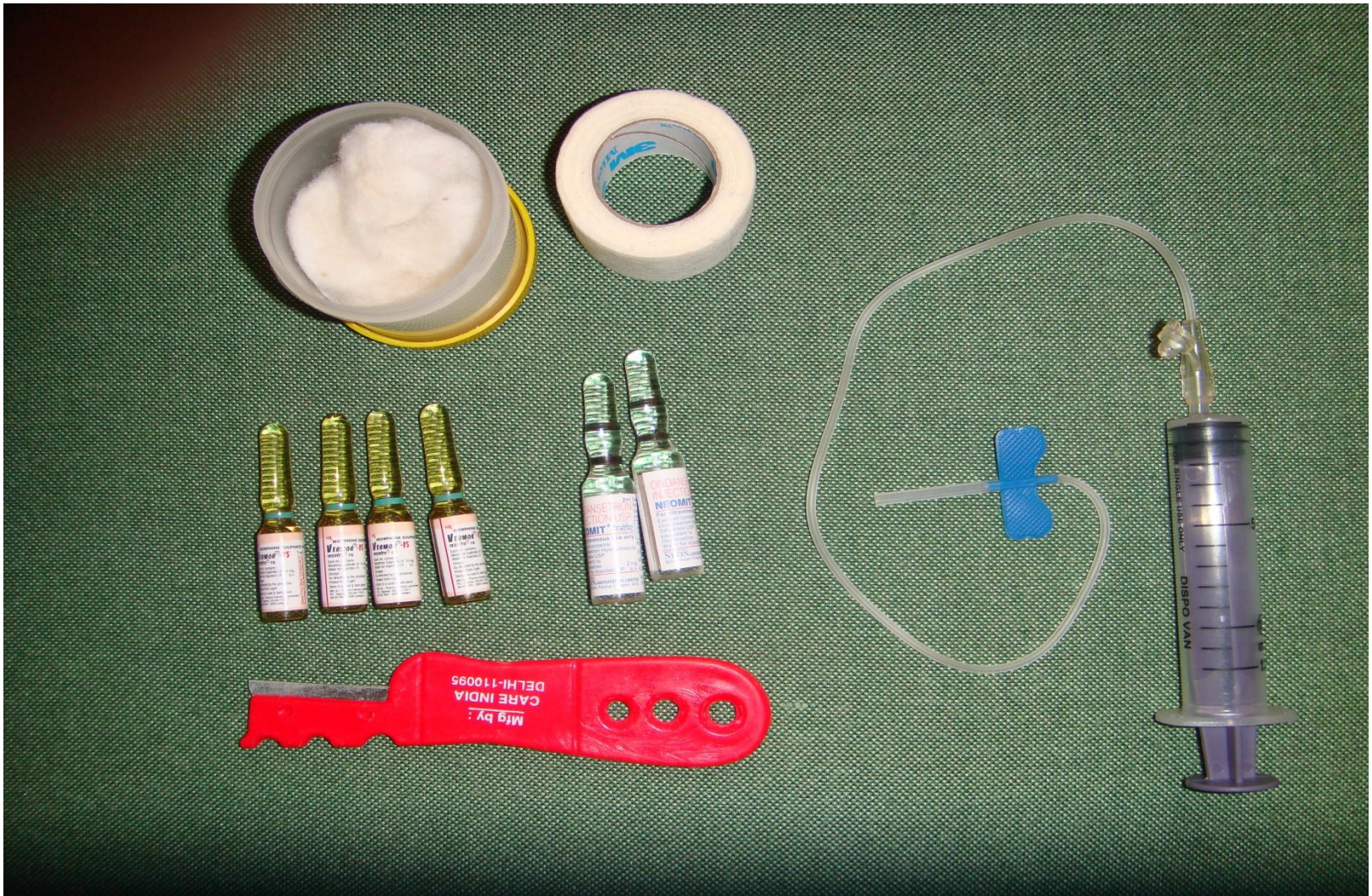
Patient in blue saree with the "Family driver"!





Equipment required

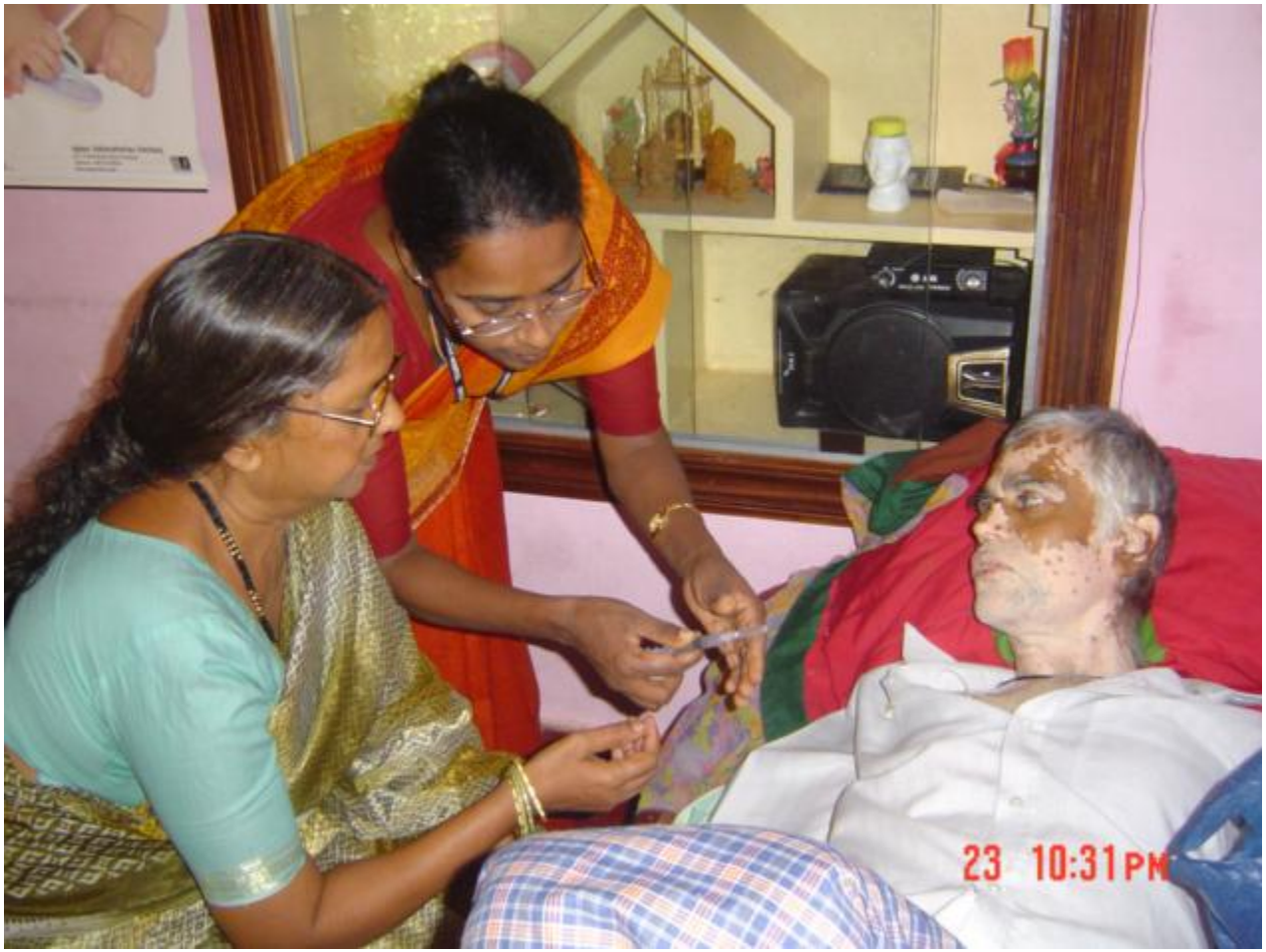
10ml syringe, 23 – 25 g butterfly needle with cannula ampules, ampule cutter, spirit swabs, plaster roll




13 10:07PM

Comfortable and happy at home – few days before death

Empowered!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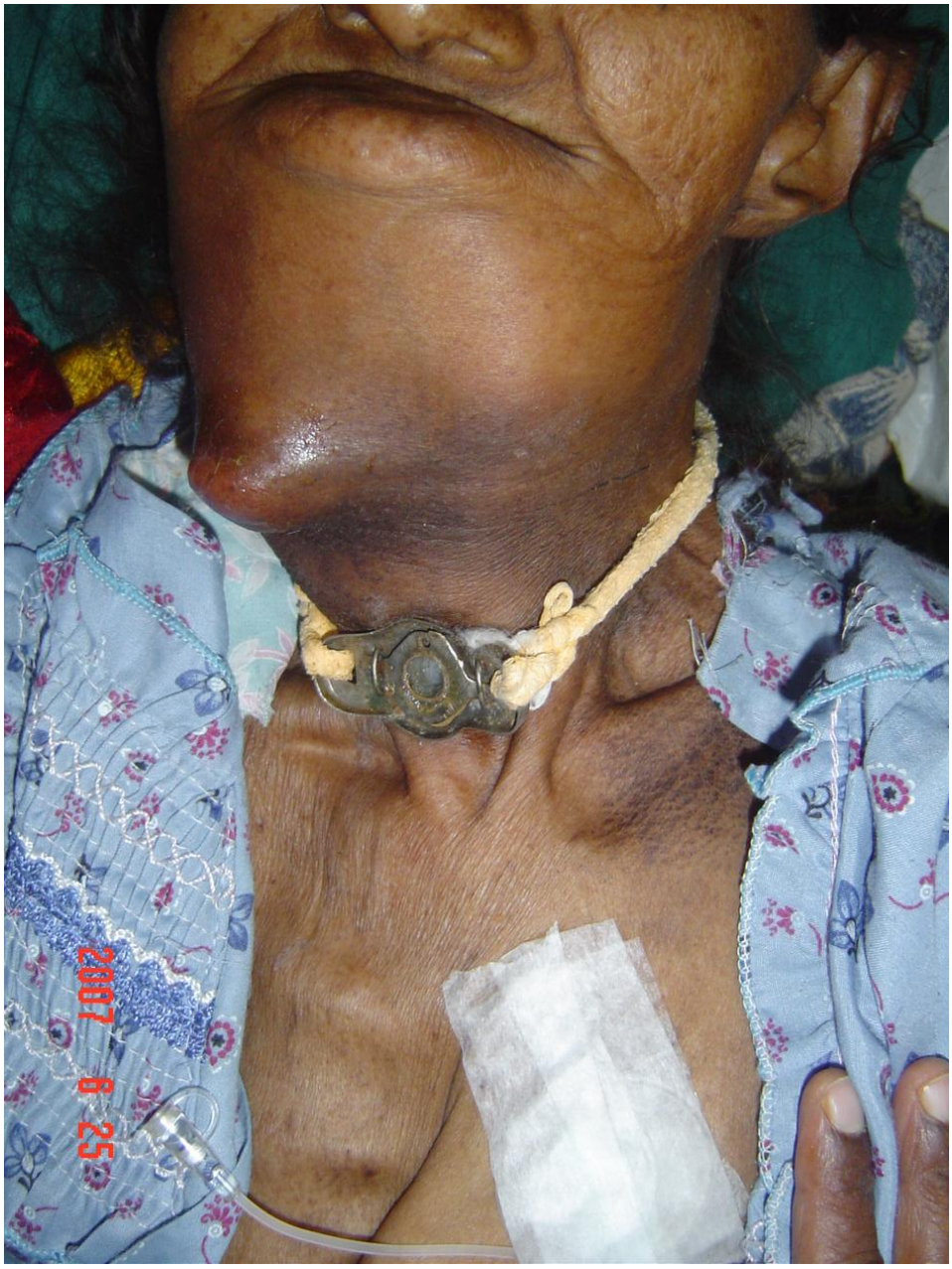

2007 8 25


2007 6 25

Sedated & comfortable, able to sleep in his mother's lap

Nurses checking bowel sounds

Team work to complete various tasks

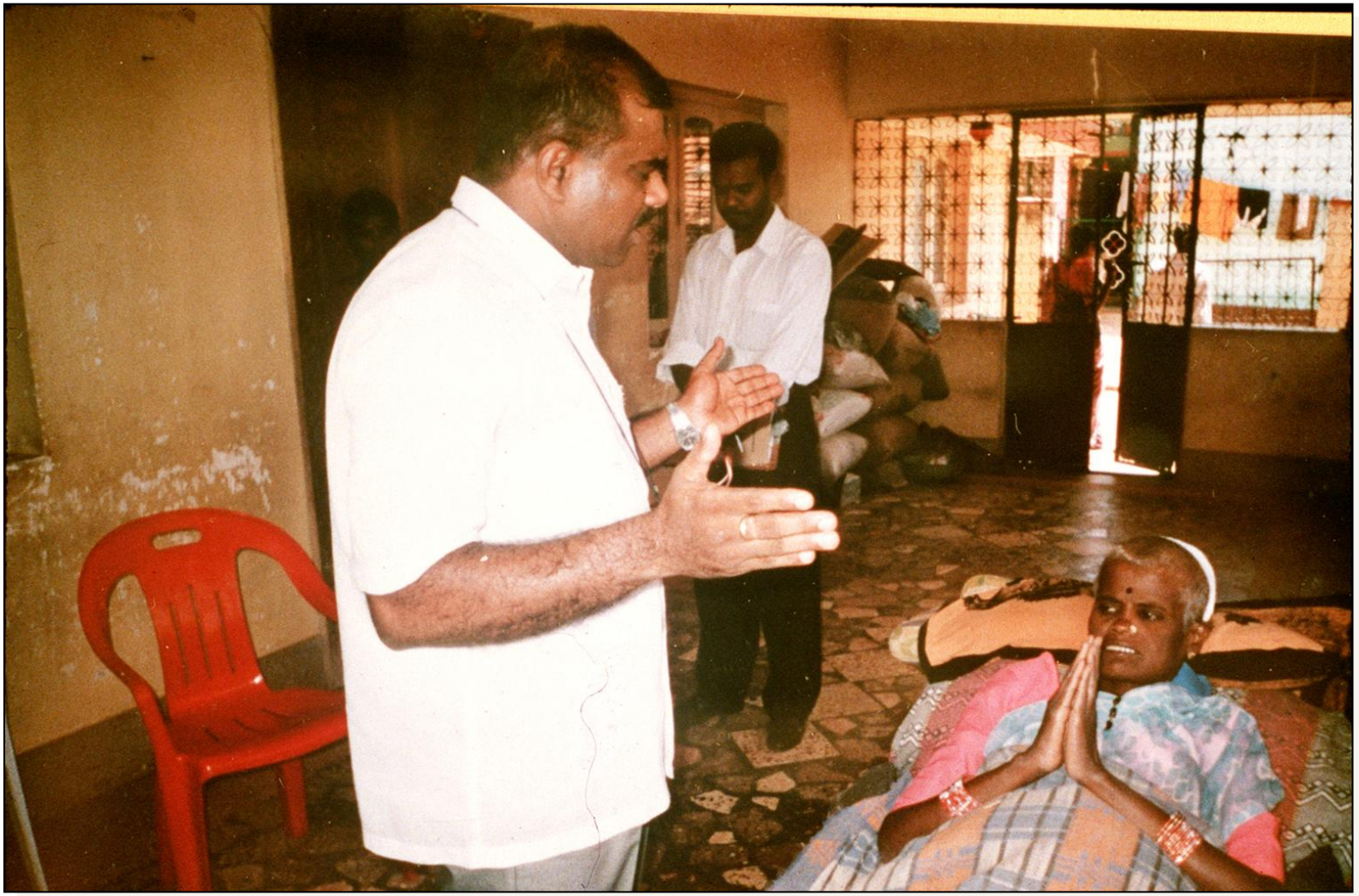
Filling a waterbed can be a challenge in the village

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

Pal-Onc Clinic

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

Hospice and Home Care in Bangalore India

A joint vision a committed partnership to meet a forgotten need

"I Came That They May Have Life." JESUS

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

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

Palliative Care Team

Introduction

In India provision of palliative care service remains low and the coverage is fragmented (1). The quality of service also needs evaluation by audit and by 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).

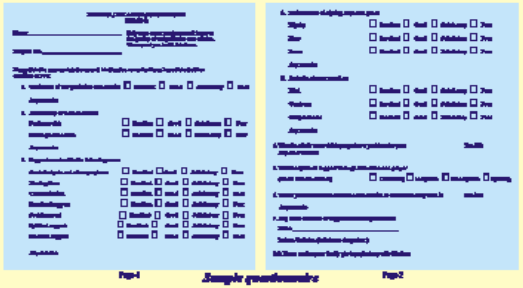
The Bangalore Baptist Hospital started its palliative care service in 1995 and palliative home care was added in 1998. Feedback on our palliative home care service was obtained through a questionnaire given to families after the death of their loved one. A total of 100 responses are analyzed and presented.

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 comment.

100 such responses over a three year period are analyzed and presented. A sample questionnaire is as shown in this presentation.

All set and ready to go



Sample questionnaire

Family conference

Teaching wife to give S/C injections

Analysis of 100 responses

Conclusions: • 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 service as and when they were received. • 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 attempt 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 Gear – Guidelines for managing the last days of life in adults, Dec 2001

Project ‘EPHATHA’ (Be opened)
KM Church volunteer’s training

Koramangala Methodist Church

PAIN & PALLIATIVE CARE SOCIETY

PAIN & PALLIATIVE CARE SOCIETY - IPM CALICUT-INDIA WHO COLLABORATING CENTRE

CHRISTIAN MEDICAL ASSOCIATION OF INDIA

FELLOWSHIP

IN

PALLIATIVE MEDICINE

&

PALLIATIVE NURSING

NFPM - Faculty meeting

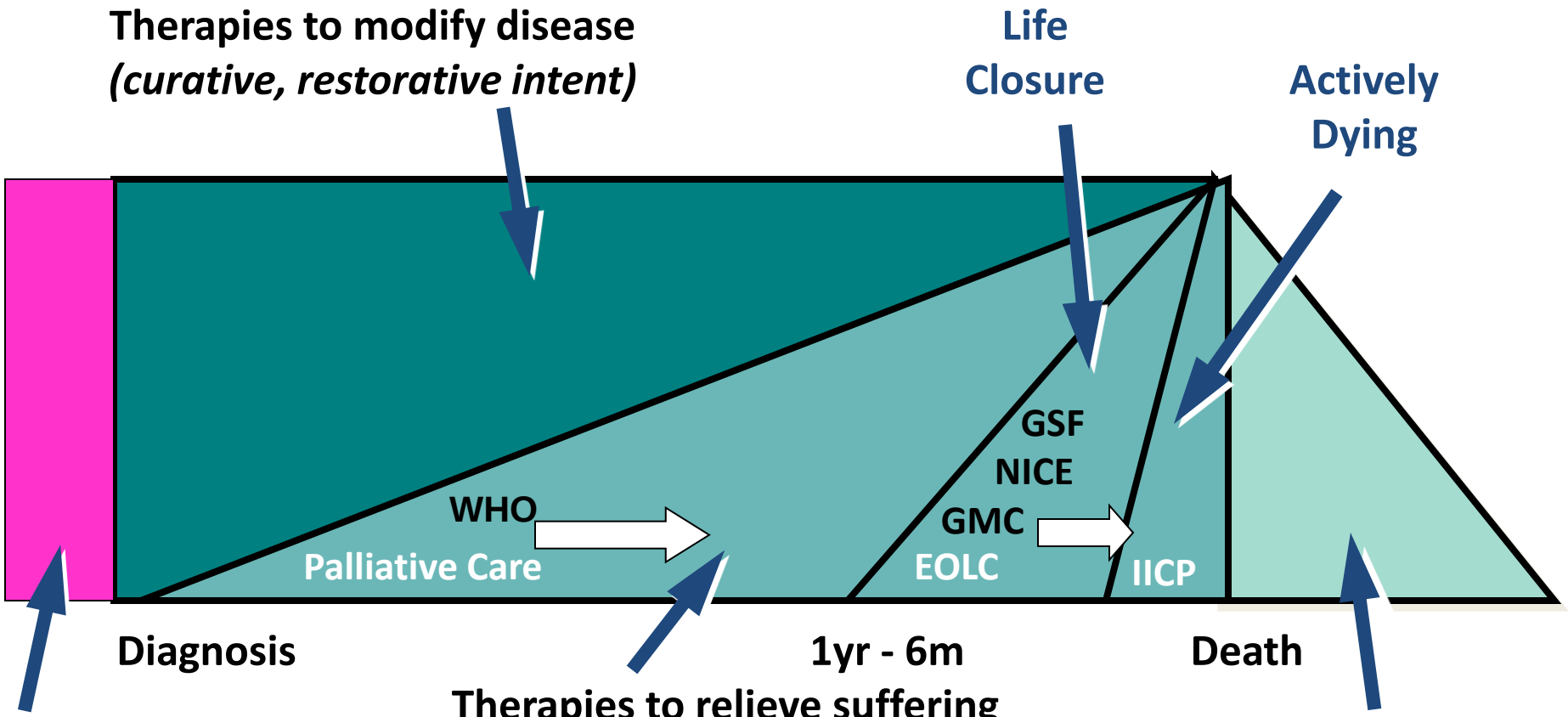
A spin-off of Palliative Care!

A state-of-the-art
Linear accelerator RT facility
By continued support from
Wake Forest University,
Winston-Salem, NC, USA

Kurian Foundation Grant
Rural PC project (200 / 500)

The continuum of palliative care

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



Joining hands!
IAPC & ISCCM

Indian Journal of Palliative Care
Sept – Dec 2014 – Vol 20/Issue 3

Position Paper

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

Stanley C Macaden, Naveen Salins[1], Maryann Muckaden[1],
Priyadarshini Kulkarni[2], Anjum Joad[3], Vivek Nirabhawane[4], Srinagesh Simha[5]

Indian Journal of Critical Care Medicine
Sept 2014 – Vol 18, Issue-9

Guidelines

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 Salins[1], Shivakumar Iyer[2], Stanley C. Macaden[3], Jigeeshu V. Divatia, Maryann Muckaden[1], Priyadarshini Kulkarni[4], Srinagesh Simha[5], Raj Kumar Mani[6]

End of Life Care Certificate Program

ISCCM™

Indian Association of Palliative Care

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:

08.30 - 09.00	Registration
09.00 - 09.15	Inauguration
09.15 - 09.45	Introduction to EOLC: Padma Bushan Prof B. M.Hegde Retired Vice-Chancellor, Manipal University.
09.45 - 10.15	EOLC symptom management: Dr. Prince John Palliative Medicine Consultant, Asian Institute of Oncology, Mumbai
10.15 - 10.50	Process and pathway of EOLC: Dr.Vijaya Patil Professor, Department of Critical Care Medicine, Anesthesia and Pain, Tata Memorial Hospital, Mumbai
10.50 - 11.15	Tea break
11.15 - 11.45	EOLC Communication: Dr. Naveen Salins Consultant, Department of Palliative Medicine, Tata Memorial Hospital, Mumbai
11.45 - 12.15	Ethics and Legal aspects of EOLC: Dr. Farad Kapadia Senior Consultant Physician and Intensivist, Hinduja Hospital, Mumbai.
12.15 - 13.00	Panel discussion
13.00 onwards	Lunch break

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**

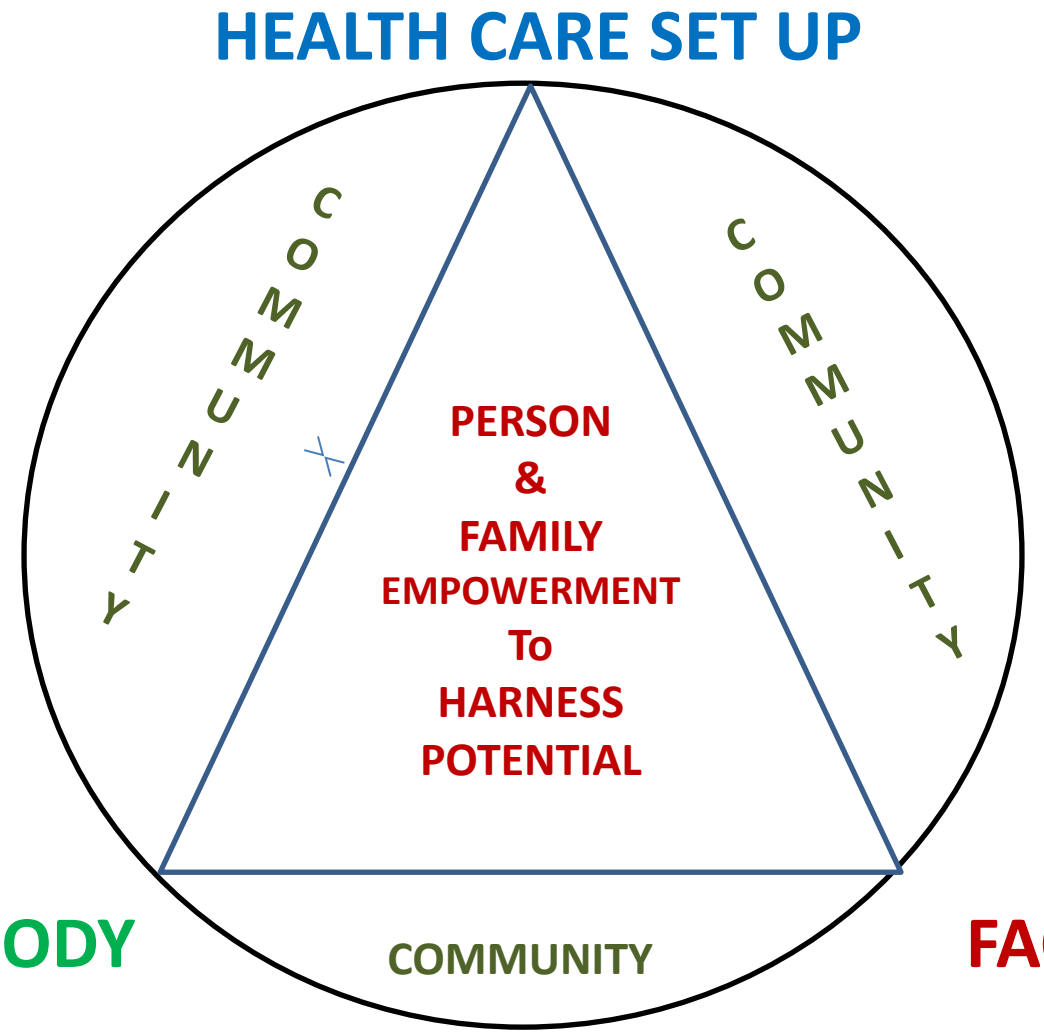
First Foundation Course at BBH – Jan 11th-13th 2016

International Collaborative for Best Care for the Dying Person

Challenges / Solutions

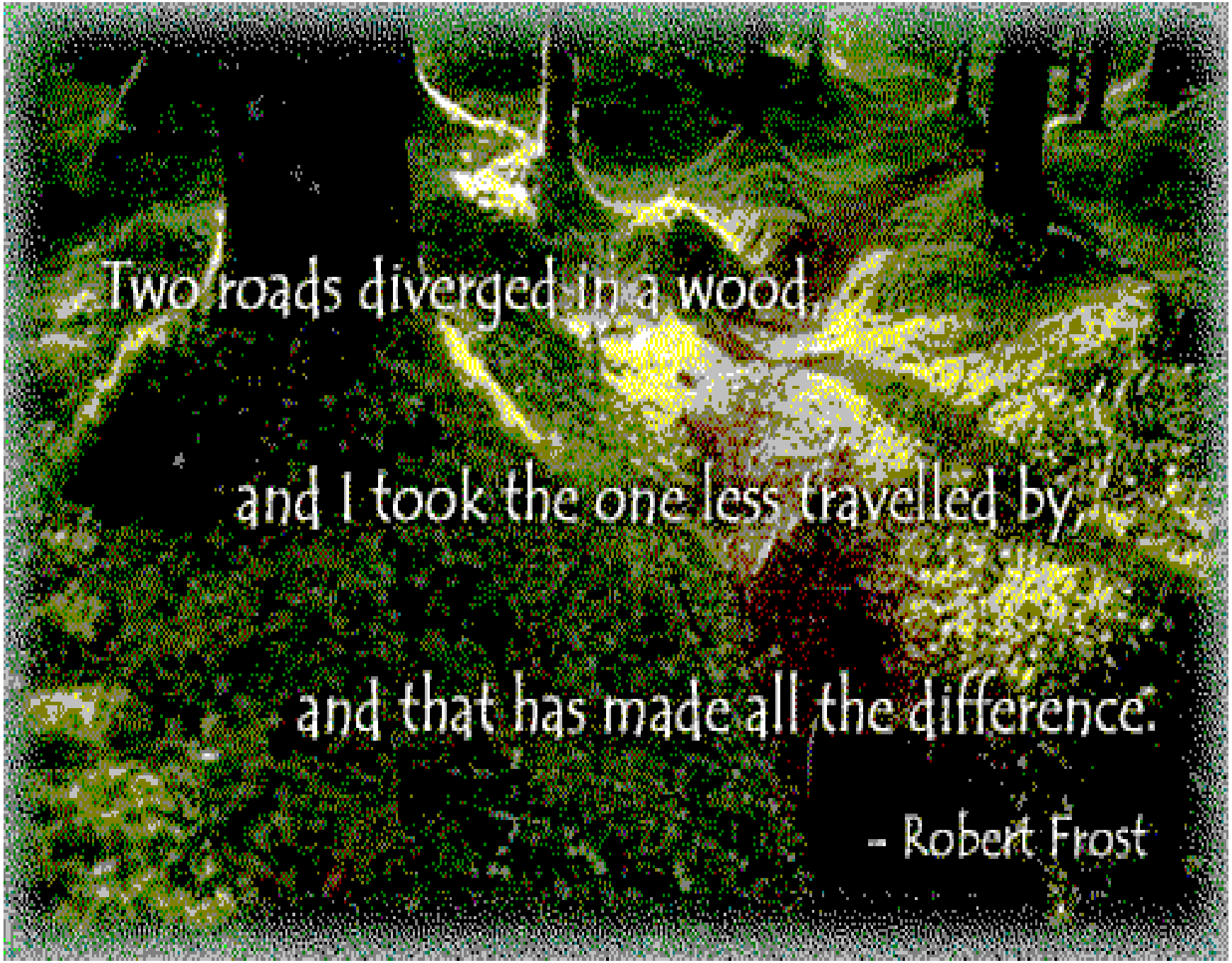
1. PC in all Health related undergraduate curricula
2. Mandatory EOLC-D certification for Drs /Nurses
3. +/- IAPC certificate course in Palliative Care
4. More integration / networking
5. Balance between coverage & quality
6. Auditing of services by NABH
7. Army of volunteers
8. Army of HCAs
9. More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

Tripartite Partnership & Stewardship



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