End Of Life Care (EOLC)

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PLAN

• Definition of EOLC
• Current situation in India
• Proactive Identification Guidance (PIG) – GSF(UK)
• International Collaborative for Best Care for the Dying Person
• Symptom control of the actively dying / Sub-cutaneous route
• Communication in EOLC
• Ethical & Legal issues
“How people die remains in the memory of those who live on”

Dame Cicely Saunders
EOLC - ?

• Is it Palliative Care in general

• Is it care in last yr/6months

• Is it care in the last 2-3 days?
• The General Medical Council defines approaching the end of life as when a person is likely to die within the next 12 months.

• The above definition is used by National Institute for Clinical Excellence (NICE) and the Gold Standards Framework (GSF).
This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) advanced, progressive, incurable conditions
(b) general frailty and co-existing conditions that mean they are expected to die within 12 months
(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition
(d) life-threatening acute conditions caused by sudden catastrophic events
Gold Standards Framework GSF- UK

• GSF is a framework to deliver a 'gold standard of care' for all people nearing the end of life. 'It's about living well until you die‘

• It helps clinicians identify patients in the last year of life – ‘Surprise question’

• Assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose
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

WHO
Palliative Care

Preventive care
Healthy life style

Therapies to relieve suffering
improve quality of life

1yr / 6m

Death

Bereavement Care
The three main trajectories of decline at the end of life

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

- **Cancer** (n=5)
- **Organ failure** (n=6)
- **Physical and cognitive frailty** (n=7)
- **Other** (n=2)

**Function**

- High
- Low

**Time**

Death

BMJ 2008;336:958-959 (26 April)

Making a Difference
Palliative Care Beyond Cancer
Care for all at the end of life

Scott A Murray, St Columba’s professor of primary palliative care,
Aziz Sheikh, professor of primary care research and development
University of Edinburgh
The Cry of a person facing death

help me
listen to me
stay with me
remember me

Dr. Charles Corr
What is good death? Principles

• To know when death is coming, and to understand what can be expected
• To be able to retain control of what happens
• To be afforded dignity and privacy
• To have control over pain relief and other symptom control
• To have choice and control over where death occurs
• To have access to information and expertise of whatever kind is necessary
• To have wishes respected and have access to any special needs
• To have control over who is present and who shares the end
• To be able to leave when it is time to go and not to have life prolonged pointlessly
Role of curative treatment in life limiting illness

- Cancer – 20% helped by curative treatment
- End stage renal disease - 6% helped by transplant
- HIV /AIDS – ? 6% AIDS related deaths

In all the above situations the need is for good comprehensive care, including Palliative care, throughout the entire course of the illness.
End-of-life care: the neglected core business of medicine

Despite several reports and guidelines over the past few years on the importance of managing end-of-life care, knowledge and confidence among hospital doctors is still far from ideal when looking after those in the last few days, weeks, months, or even years of their lives.

The Lancet, 31 March 2012
Volume 379, Issue 9822, Page 1171
Selecting patients who need palliative care
Using Gold Standards Framework (GSF - UK)
Proactive Identification Guidance (PIG)

• Step 1. Surprise Question

• Step 2. General Indicators of decline and increasing needs

• Step 3. Specific Clinical Indicators related to 3 trajectories

  • http://www.goldstandardsframework.org.uk
Patients with cancer who die in a hospital or ICU have worse QoL compared with those who die at home, and their bereaved caregivers are at increased risk for developing psychiatric illness. Interventions aimed at decreasing terminal hospitalizations or increasing hospice utilization may enhance patients' QoL at the EOL and minimize bereavement-related distress.

(Alexi A. Wright et al J Clin Oncol. 2010 October 10; 28(29): 4457–4464)
Place of Death: Correlations With Quality of Life

![Bar chart showing quality of life measures for different places of death.](chart_image)

- Quality of Life: Home with Hospice (6.6), Home (7.3), Hospital (5.3), Intensive Care Unit (5.0)
- Physical Comfort: Home with Hospice (6.6), Home (5.9), Hospital (4.7), Intensive Care Unit (3.6)
- Psychological Well-Being: Home with Hospice (7.0), Home (6.0), Hospital (6.0), Intensive Care Unit (6.0)

Significance levels:
- Quality of Life: $P = .003$
- Physical Comfort: $P < .0001$
- Psychological Well-Being: $P = .02$
ICU

- Testing ground for our collective expertise, knowledge, wisdom, ethics and attitudes
- 20 – 25% pts should not be there
- High cost in every aspect
- Inappropriate interventions - defensive medicine - exploitation
- Palliative care interface like ‘high tide’ can raise the whole standard of care
How our patients are dying

• 83% of healthy Indian population – prefer to die at home (Kulkarni et al Pune study IJPC 2014) – but mostly they die in the hospital

• 78% of patients with advanced illness in end of life phase in ICU left hospital against medical advice (LAMA) due to lack of resources

• Almost all LAMA patients did not receive any form of symptom relief measures in end of life period and died miserably

• Patients are dying in the wards and at home with no symptom relief, health related communication or support

• Significant number of patients dying with advanced illness in ICU with needless inappropriate interventions done – most of these patients dying alone in pain and distress.
Is dying costly in India?

• >80% of health care spending in India is out of pocket
• In most of the cases, financial resources are spent on last few days of life – mostly for high end needless medical interventions with no outcomes
• Maximum amount of money is spent on investigations (usually done for recording purposes only)
• Out of pocket spending pushes over 20 million patients into poverty every year
• This requires a huge attitudinal shift among health care providers as current medical education is based on Acute Model of Care (i.e. Diagnose and Treat).
End result

• Defensive medicine
  – due to lack of knowledge in HC professionals
  - lack of adequate policy for EOLC
  - due to lack of supportive laws for EOLC
• Commercial medicine
  - Capitation fee based medical education
  - Greed has eroded trust people have in medical profession

• Families are financially ruined & scarred for life
QUALITY OF DEATH INDEX - 2010

India

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

The quality of death
Ranking end-of-life care across the world
A report from the Economist Intelligence Unit
Commissioned by LIEN

Economist Intelligence Unit
Quality of death Index – 2015

1. UK
2. Australia
3. New Zealand
4. Ireland
5. Belgium
6. Taiwan
7. Germany
8. Netherlands
9. US
10. France
11. Canada
12. Singapore
13. Norway
14. Japan
15. Switzerland

66. Malawi
67. India
68. Columbia
69. Ukraine
70. Ethiopia
71. China
72. Botswana
73. Iran
74. Guatemala
75. Dominican Republic
76. Myanmar
77. Nigeria
78. Philippines
79. Bangladesh
80. Iraq
A Professional Consensus

Limiting life-prolonging interventions and providing palliative care towards the end-of-life in Indian intensive care units*


‘Dying can be a peaceful event or a great agony when it is inappropriately sustained by life support’ – Roger Bone
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
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 Salins¹, Shivakumar Iyer², Stanley C. Macaden³, Jigeeshu V. Divatia, Maryann Muckaden¹, Priyadarshini Kulkarni⁴, Srinagesh Simha⁵, Raj Kumar Mani⁶
What is Medical futility / inappropriate

The idea of futility is not new. The famous Hippocratic corpus included a promise:

“First I will define what I conceive medicine to be. In general terms, it is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless”
Recognizing Medical Futility –
Some clinical situations

• Advanced age coupled with poor functional state due to one or more chronic debilitating organ dysfunction. For example, end stage pulmonary, cardiac, renal or hepatic disease for which the patient has received/declined standard medical/surgical options

• Severe refractory illnesses with organ dysfunctions unresponsive to a treatment

• Coma (in the absence of brain death) due to acute catastrophic causes with nonreversible consequences such as traumatic brain injury, intracranial bleeding, or extensive infarction
Recognizing Medical Futility – Some clinical situations

- Chronic severe neurological conditions with advanced cognitive and/or functional impairment with little or no prospects for improvement – For example, advanced dementia, quadriplegia, or chronic vegetative state

- Progressive metastatic cancer where treatment options have failed

- Post cardio respiratory arrest with prolonged poor neurological status

- Any other comparable clinical situations coupled with a physician prediction of low probability of survival
Guidelines - End-of-Life Care Process

1. Physician's objective and subjective assessment of the Dying Process/Medical Futility
   - Prognostic Uncertainty - expert opinion
   - Consensus among all caregivers
     - Honest, accurate and early disclosure of the prognosis to the family
     - Discussion and communication of all modalities of EOLC with the family
     - Shared decision making - consensus through open and repeated discussions
     - Transparency and accountability through accurate documentation
     - Ensure consistency among caregivers
   - Pending Conflict Resolution - Continue full support/second opinion/discussion with senior family members/psychologist's consultation/independent medical panel/ethics committee

2. Implementing the process of withholding or withdrawing life support
   - Effective and compassionate palliative care to patient and appropriate support to the family
   - After Death Care
   - Bereavement Care Support
   - Review of the Care Process
Guidelines Summary

1. Physicians objective and subjective assessment of medical futility
2. Consensus among all care givers
3. Honest, accurate, and early disclosure of the prognosis to the family
4. Discussion and communication of modalities of end-of-life care
5. Shared decision-making
6. Transparency and accountability through accurate documentation
7. Ensure consistency among caregivers
8. Implementing the process of withholding or withdrawing life support
9. Effective and compassionate palliative care to patient and appropriate support to the family
10. After death care
11. Bereavement care support
12. Review of care process
Goals of communication

• Establishing consensus
• Providing accurate and appropriate information which will facilitate further decision making and planning
• Eliciting and resolving the concerns prompted by end-of-life decisions (EOLD)
• Establish trust and therapeutic bond.
• Facilitate realistic hope in an adverse situation.
Legal Aspects - summary

There is a need to develop laws specifically dealing with limitation of therapeutic measures.

But there is enough precedent in international law to support such limitation.

Indian law (as it stands currently) affords sufficient protection to well intentioned ethical clinicians.

There is no need to practice treatment limitation “furtively.”

Professional consensus needs to be built; used as the best protection against civil suits.
Ethics of Palliative Care

- Ethics of Palliative Care are those of Medicine in general

- Health professionals have dual responsibility
  - to preserve life
  - to relieve suffering

- At the end of life relief of suffering is more important as preserving life becomes increasingly impossible
IAPC & ISCCM
Poster presented at the Inaugural Conference of the International Collaborative Nov 19, 2014 at Lund, Sweden

IAPC became an Organisation Member on 25/8/15

Joining hands for seamless best care of the dying

Stanley C Macaden1, Navaneet Salins2, Maryann Muckaden2, Priyadarshini Kulkarni2, Srinagesh Simha3, Rajkumar Mani3, Shivakumar Iyer3, Jigeesu V. Divatia4, Sheila Naiman Myatra
1Christian Medical Association of India, New Delhi, 2Tata Memorial Centre, Mumbai, 3Challapalli Palliative Care and Training Centre Pune, 4Karunashraya Hospice Bangalore, 5Saket City Hospital, New Delhi, 6Bharati Vidyapeeth University Medical College, Pune. (All from India)

Background

- Millions of people in India with advanced life threatening illnesses are dying with needless pain and suffering.
- Study conducted by the Economic Intelligence Unit, Lien foundation 1011 -quality of death scores in India was least among the 40 countries studied.
- The report from Human Rights Council titled “Unbearable Pain - India’s obligation to Ensure Palliative Care” - people in India with advanced illnesses are dying with unrelieved pain and suffering with or without available essential symptom relief medications.
- At present in India only 1-3% of the population have access to palliative care and less than 1% has access to Morphine.
- More than 80% of Indians pay for their medical expenses out of pocket and most of it is spent on unnecessary medical expenses for the last few days of life.
- Health care providers in India lack knowledge about end of life care, and tend to practice defensive medicine due to lack of adequate policy or legal protection backing their practices.
- Hence it is important to address the end of life care issues at all levels (i.e. policy, legal stand point, infrastructure to provide end of life care, availability of essential medications and end of life care education).

Action Research

Conception

Indian Association of Palliative Care (IAPC) and Indian Society of Critical Care Medicine (ISCCM) collaborated in April 2014 to bring the end of life care needs of India. The action research planned was to create an integrated care plan for the dying which will primarily facilitate end of life care policy and education.

Objectives

1. Indian Association of Palliative Care will come out with a position statement on EOL.
2. Policy Document for end of life care will be prepared jointly by ISCCM and IAPC
3. Implementation in Supreme Court
4. End of life care certificate program

Results

1. IAPC published a consensus position statement on End of Life Care in Indian Journal of Palliative Care
2. Joint position statement of IAPC and ISCCM was published in Indian Journal of Critical Care Medicine
3. Nation wide launch of End of Life Care Certificate Program
4. Implementation in the highest court of the country to provide an unambiguous legal stand point for good end of life care.

Position Paper

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Future initiatives

1. Continuing advocacy measures for good end of life care - Access to palliative and end of life care is a human right and all patients are entitled for dignified death
2. Persuade Government of India to take urgent measures towards a legislation supporting good end of life care and motivate all health institutions to have a end of life care policy
3. Initiate capacity building measures and create infrastructure for end of life care provision
4. Create basic minimum standards in end of life care education and integrate end of life care education in health curriculum
5. Establish end of life care standards and accreditation delivery through national/international accreditation agencies.
6. Dr. Stanley Macaden named lead for India to recruit active centers for a pilot study to apply the new guidelines from the Lund inaugural conference of the ‘International Collaborative for Best Care of the Dying’.

Acknowledgement

1. Indian Association of Palliative Care
2. Indian Society of Critical Care Medicine
3. Tata Memorial Centre, Mumbai
4. Karunashraya Hospice, Bengaluru
5. Wisdom Hospice, Rochester, Kent, UK
Ten key principles of care for the dying patient

1. Recognition that the patient is dying
2. Communication with the patient (where possible) and always with family and loved ones
3. Spiritual care
4. Anticipatory prescribing for symptoms of pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnoea
5. Review of clinical interventions should be in the patient’s best interests

Ten key principles of care for the dying patient

6. Hydration review, including the need for commencement or cessation
7. Nutritional review, including commencement or cessation
8. Full discussion of the care plan with the patient and relative or carer
9. Regular reassessment of the patient
10. Dignified and respectful care after death

Conclusion

• During EOLC, goal of treatment should shift from cure to comfort
• The Joint Policy of the ISCCM and the IAPC provides the basis on which doctors can practice good medicine, and provide optimal care to their patients when death is imminent. Individual practitioners must adapt these to the appropriate socio-cultural context for their patients and areas of practice.
• Fear of legal implications should not deter physicians from providing the best and ethical care to their patients.
• ELICIT has submitted a draft EOLC Bill which the SC has referred to Parliament
• We need honest, transparent and compassionate communication and meticulous documentation together with effective palliative care aiming at ensuring a good death for the patient
• ‘Project India’ of the International Collaborative for Best Care for the Dying Person aims to improve care during the actively dying phase
Equipment required
10ml syringe, 23 – 25 g butterfly needle with cannula, ampules, ampule cutter, spirit swabs, plaster roll
Poor pt with a large sarcoma – severe pain, fungating ulcer, malodour
Wife giving SC injections
Person comfortable, sleeping
Wife wanted this picture
He was able to be roused and sit up
Comfortable at home with his family
Husband of pt fully empowered to give SC medications at home
Wife being taught
Lady with Ca larynx fairly comfortable at home on oral meds
Not able to swallow meds
Able to take only sips of fluid
Anxious & distressed due to dyspnoea
SC needle placed on lat aspect of arm
Sedated and comfortable with SC medications
Sedated & comfortable, able to sleep in his mother’s lap
“Death is not extinguishing the light. It is putting out the lamp because dawn has come.”

R. Tagore
Christian Hope

• Hope in the Lord JESUS CHRIST

• “I have come that they may have life and that they may have it more abundantly” – John 10:10

• “For God so loved the world that He gave His only begotten Son, that whoever believes in Him should not perish but have eternal life” - John 3:16
Thank You
“Death is not extinguishing the light. It is only putting out the lamp because the dawn has come.”

R. Tagore
Christian perspectives

• Christ clothes us with His righteousness & we are healed in Him.

• Isaiah 61:10 – Robes of righteousness

• 1 Corinthians 15:53,54 - immortality
There is surely a FUTURE HOPE for you, and your HOPE will not be cut off.

Proverbs 23:18

THEWORDFORTHEDAY
For I know the plans I have for you,” declares the LORD, “plans to prosper you and not to harm you, plans to give you hope and a future.”

Jeremiah 29:11
Christian Hope

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