# EOLC: Integrated care of the dying

Director-Strategy and COVID-19 Management Yashoda Superspecialty hospital, Kaushambi, Ghaziabad

#### What is a "good death"

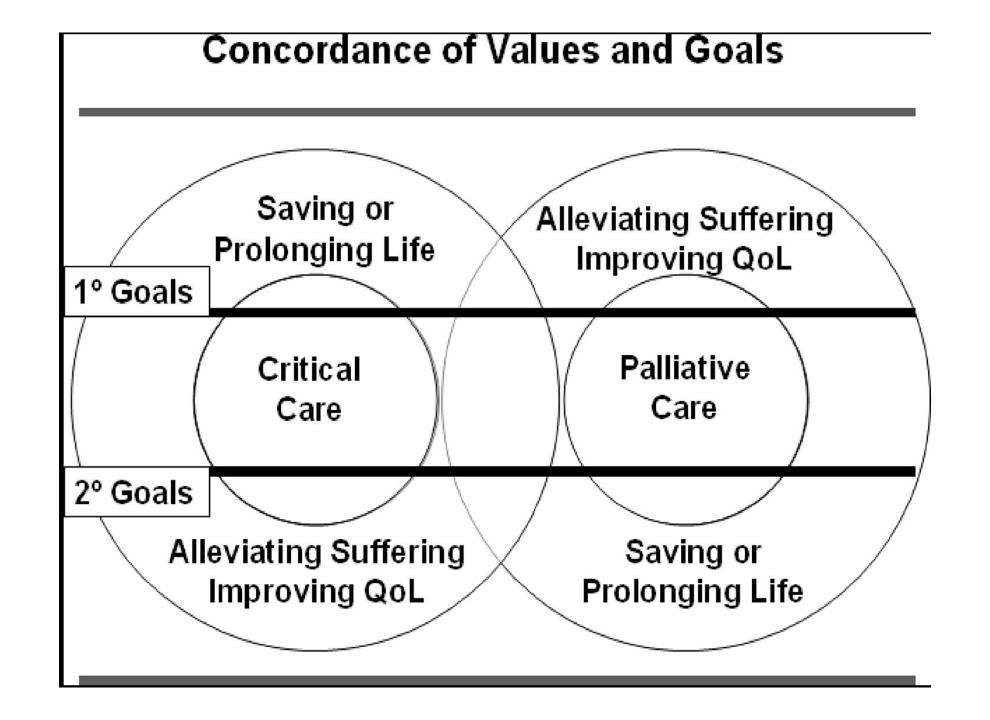
- Free from pain and distress and avoidable treatment burdens
- Happening in the preferred place, which isn't a "medicalised" environment
- In the presence of loved ones
- Having had the time to prepare, for goodbyes, reconciliations and life closure
- At peace, accepting
- Spiritual ambience

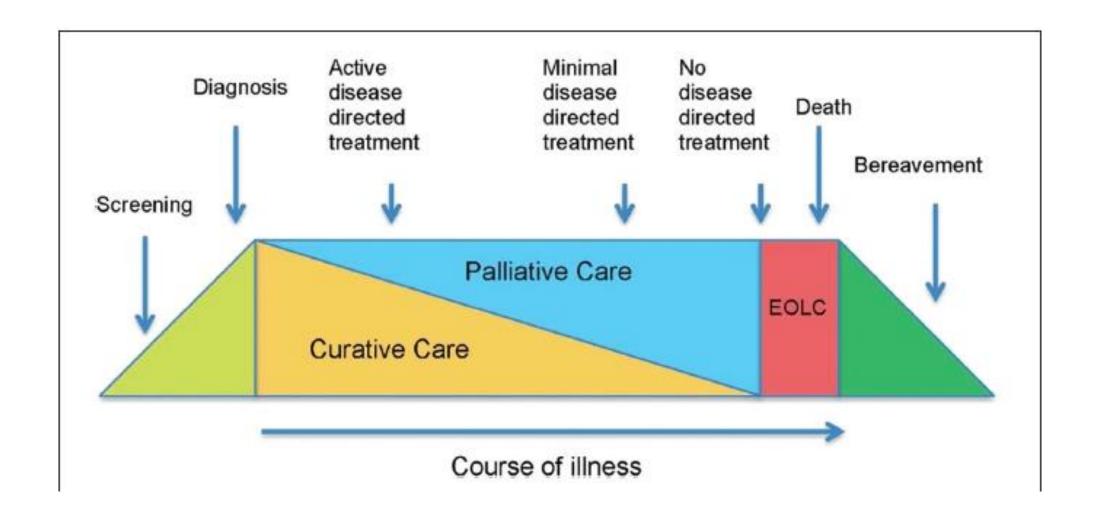
#### WHO definition

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

Let's look at our goals in critical illness...

- Restoring health
- Extending life
- Relieving pain and suffering





#### "Intensive-palliative" care

- Palliative care begins with CCM and continues even after CCM fails
- It is integral to care whatever the age, diagnosis or prognosis
- For both the dying and the survivors
- Critical care skills must include palliative care competencies.
- Specialist palliative care consultation wherever available

#### Distress control is important in critical care

- To alleviate excessive stress response
- A quality measure of patient and family satisfaction
- Holistic treatment is the whole hearted response to illness
- ?Reduction of mortality

#### Improving ICU palliative care

Intensive Care Med (2014) 40:235–248 DOI 10.1007/s00134-013-3153-z

REVIEW

Kathleen Puntillo Judith Eve Nelson David Weissman Randall Curtis Stefanie Weiss Palliative care in the ICU: relief of pain, dyspnea, and thirst—A report from the IPAL-ICU Advisory Board

### Components of palliative care in the ICU

- Relief of distressing symptoms (physical, psychological, spiritual)
- Effective communication in setting care goals
- Patient-centered decision making
- Support to family
- Consistency across care settings

#### Symptom control

- Pain : about 70% report moderate-severe pain
- Anxiety /agitation
- Dyspnea: 34%
- Thirst: 71%
- Constipation

#### Procedures associated with pain

- Turning
- Suctioning
- Wound care and dressing
- Arterial puncture
- Drain, Chest tube removal
- Insertion of lines
- Femoral sheath removal

## Symptom assessment tools: for communicative patients

- Self-report : Numerical Rating scale (NRS) 0-10
- Self report: Visual Analog Scale (VAS) 0-10
- Multidimensional scales: short questionnaires

## Symptom assessment for non communicative patients

- Behavioral assessment
  - Richmond Anxiety Agitation Score(RAAS)
  - Behavioral Pain Scale (BPS)
  - Critical Care Pain Observation Tool (CPOT)
  - Respiratory Distress Observation Scale (RDOS)
  - Confusion Assessment Method (CAM-ICU) scale
- Proxy symptom assessment
- Assumed symptom presence

#### Treatment strategies: Pain

- Opioids
- Non opioids: paracetamol
- Ketamine, nefopam
- Cyclo oxygenase inhibitors
- Gabapentin, carbamazepine, newer agents
- Regional anaesthesia
- Anxiolytics
- Haloperidol, clonidine, quetiapen
- Bowel regimen
- Non pharmacological: massage, relaxation therapy, music

#### Treatment strategies: Dyspnea

- NIV: not always relieves distress
- Oxygen: not useful for alleviation of dyspnoea
- Positioning : upright with arms elevated and supported
- Opioids: evidence based for chronic refractory dyspnea and terminal care
- Benzodiazepines for anxiolysis
- Fan directed at face
- Graded exercise

#### Communication is crucial



#### Communication: the hardest skill...

- Key to quality palliative care
- Family meetings/conferencing
- Content: eliciting patient's values, setting goals
  empathy and patience
  addressing queries without jargon
  emotional support-allowing expression
  affirming non abandonment
- Duration: more time for family to talk than to be talked to

#### Family issues

- Critical illness has profound effects on the family
- Half the family members experience anxiety, depression, post traumatic stress disorder(PTSD)
- Face financial burdens and practical difficulties
- Post intensive care syndrome-family is a measure of family morbidity

## Tried and tested measures to reduce family distress

- Open and repeated communication
- Allowing family participation in patient care: bathing, feeding, turning, mouth care
- Liberal visitation time. Spending time with the patient

#### Measuring quality of care

- Measuring frequency of pain and dyspnea assessment and response
- Measuring side effects: eg, Frequency of bowel movement
- Measuring patient and family satisfaction: QODD, FSI-ICU,QOC.



#### Coming together to care for the dying in India

Raj Kumar Mani

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

Ind J Crit Care Med; Sept 2014;18:615-635

#### What is inappropriate treatment?

- When a patient's treatment is inconsistent with professional knowledge or beliefs and non concordant with patient's wishes.
- Upto 23%-33% of ICU care may be disproportionate in one large series among 85 ICUs across Europe
- ICU care providers agree that excessive care is a true issue in the ICU

## What is our response to terminal suffering?

- Defensive medicine and mutual mistrust
- Hiding from moral dilemmas behind legal ambiguities
- No freedom to practice ethically and confidently ("moral distress")
- Lack of awareness, knowledge and training in bioethics and terminal care

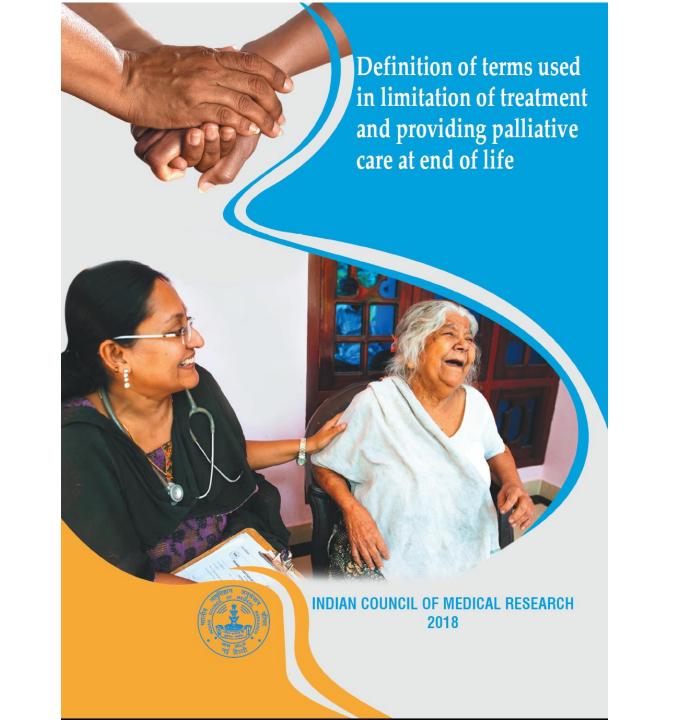
#### Let's be friends with what is inevitable...

- "do everything" doesn't mean that they want machines hooked up.
- I tell them: "of course I will do everything to ensure your loved one is comfortable"

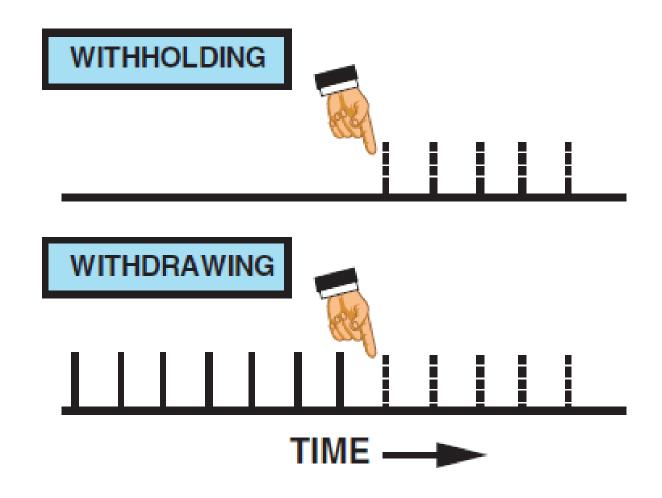
#### A three-way obligation

Medical practitioners are subject to ethical, professional and legal principles

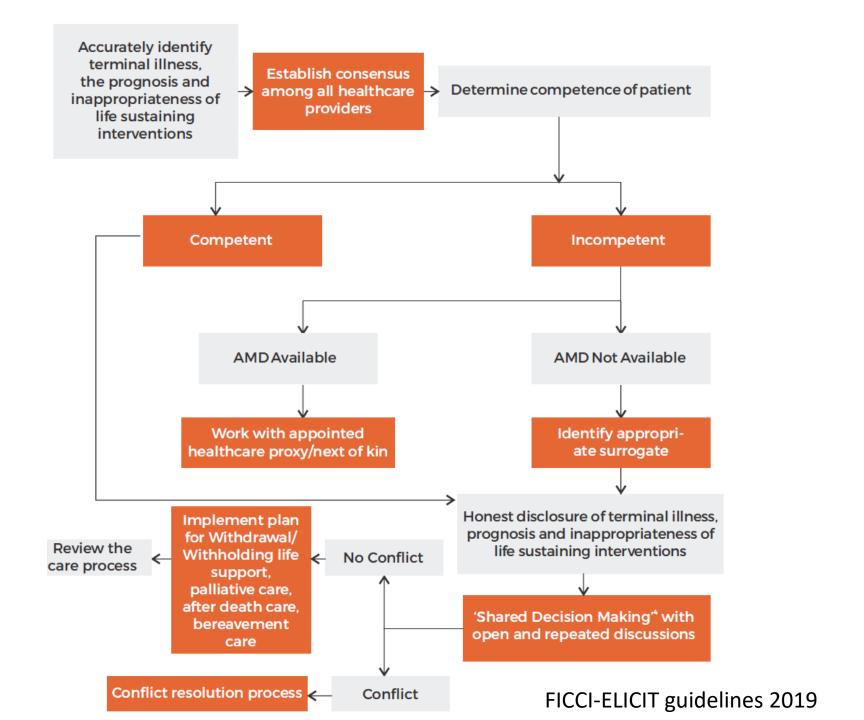
There is now a constitutional and statutory force to the Common Law right to refuse treatment



## Withholding and withdrawing are ethically the same



Vincent JL. Critical Care 2005, 9:226-229 (DOI 10.1186/cc3486)



#### **Policy Document**

Indian J Med Res 151, April 2020, pp 303-310

DOI: 10.4103/ijmr.IJMR\_395\_20



ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation'

Indian Council of Medical Research Expert Group on DNAR†

Mathur R. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation'. Indian J Med Res 2020;151:303-10

#### Conclusions-1

- Foregoing of life support (FLS) denotes WD,WH or DNAR
- It is an important decision making towards improving end of life care
- These decisions are complex needing open and sensitive communications, shared decision-making and transparency
- Quality palliative care replaces curative treatments

#### Conclusions-2

- Recent landmark Supreme Court judgments have validated patient Autonomy and the rights to AMD and Foregoing of life-prolonging treatment
- Procedures recommended by the SC are problematic and efforts to simplify are on.
- Professional bodies have laid out pragmatic procedural guidelines in line with the rest of the world