Why Patients and Families should have the Last Word

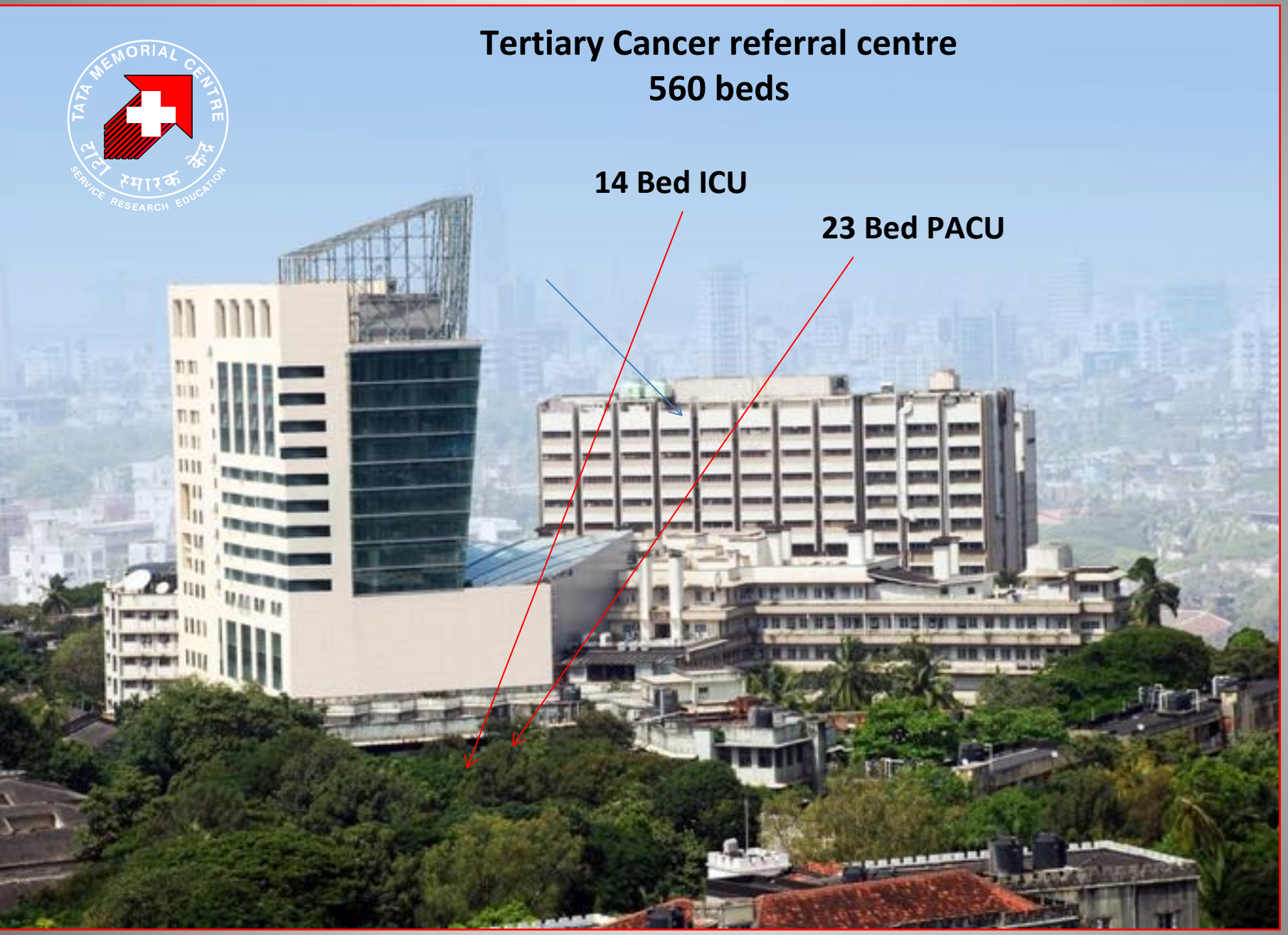
JV Divatia

Professor and Head
Department of Anaesthesia, Critical Care & Pain
Tata Memorial Hospital, Mumbai

인도에서 인사말.
초대해 주셔서 영광입니다.
감사합니다.

Greetings from India
Thank you for inviting me
I am deeply honoured

Tata Memorial Hospital



David vs. Goliath

Goliath	David
Crippen	Divatia

Paternalism

- Physicians do not have a responsibility to provide **futile or unreasonable** care even if a patient or surrogate insists on it
- Physicians need not merely furnish all services asked of them
- Professional obligation and a **social sanction** to provide only therapies that are beneficial, to avoid harm, and to allocate medical resources wisely
- Each physician should be free to exercise his or her own medical judgment
- The medical profession as a whole may provide **futility standards** to govern the practice of its members
- **Moral integrity** of each physician serves as a limit to treatment demands.

Crit. Care Med. 1995; 23: 760–766
Bioethics. 2006 Apr;20(2):92-104.

What is Futility
Schneiderman 1990

Quantitative definition

- When physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile."

Qualitative

- Futile treatment is any treatment that "merely preserves permanent unconsciousness or that fails to end a patient's total dependence on intensive medical care

Ann Intern Med 1990;112:949-54

Surveys of Limitation of Treatment

- Members of the ATS Critical Care Section in 1990
- Some Witholding / Withdrawing over patients' or surrogates' objections

- Forgoing of life-sustaining therapy preceded death in 90% of patients who died in the ICUs in 1992-1993.
- In 56%, "absolutely" no chance to leave the ICU alive.
- In 44% of cases judges futile, the median estimated ICU survival was 5%, and ranging between 1% and 50%!
- DNR orders were written without the consent of the surrogates of several patients

Am. J. Respir. Crit. Care Med. 1995; 151:288–292
Am. J. Respir.Crit. Care Med. 1997; 155:15–20.

John Luce
Have we gone too far?

- …in recommending that life support be withheld or withdrawn from some of our patients for whom further care would not be futile in a stringent
- …been too zealous in promoting these practices …. we have challenged patient autonomy …. without the agreement of patients or their surrogates.
- Challenging patient autonomy probably was important at one point in the evolution of our profession's view
- ***We must be very cautious in exercising our influence, if not authority, over patients and their surrogates in prompting the forgoing of lifesustaining therapy in the ICU.***

AM J RESPIR CRIT CARE MED 1997;156:1715–1718.

Changing Defintions Shifting Trends

1990

Schneiderman

No ethical obligation to provide futile Rx
need not obtain consent from patients or family members

1989

ATS Task force

Futile interventions can be limited without consent of patient or surrogate

Written policies defining the circumstances

1997

SCCM

Futile versus Nonbeneficial hence inappropriate or inadvisable Rx

Policy to limit inadvisable Rx

- be disclosed in the public record
- reflect moral values acceptable to the community
- not be based exclusively on prognostic scoring systems
- articulate appellate mechanismsbe recognized by the courts

Ann. Intern. Med. 1991;115:478–485
Ann Intern Med 1990;112:949-54
Crit. Care Med. 1997; 25:887–891

206 patients
Request for ICU admission

105 (51%) Admitted to ICU
Mortality 45.7%

How good is our Judgement?

101 (49%) Denied ICU admission

54 (53%) Too sick
51 no Rx
18 moribund
Mortality 74%
26% survived!

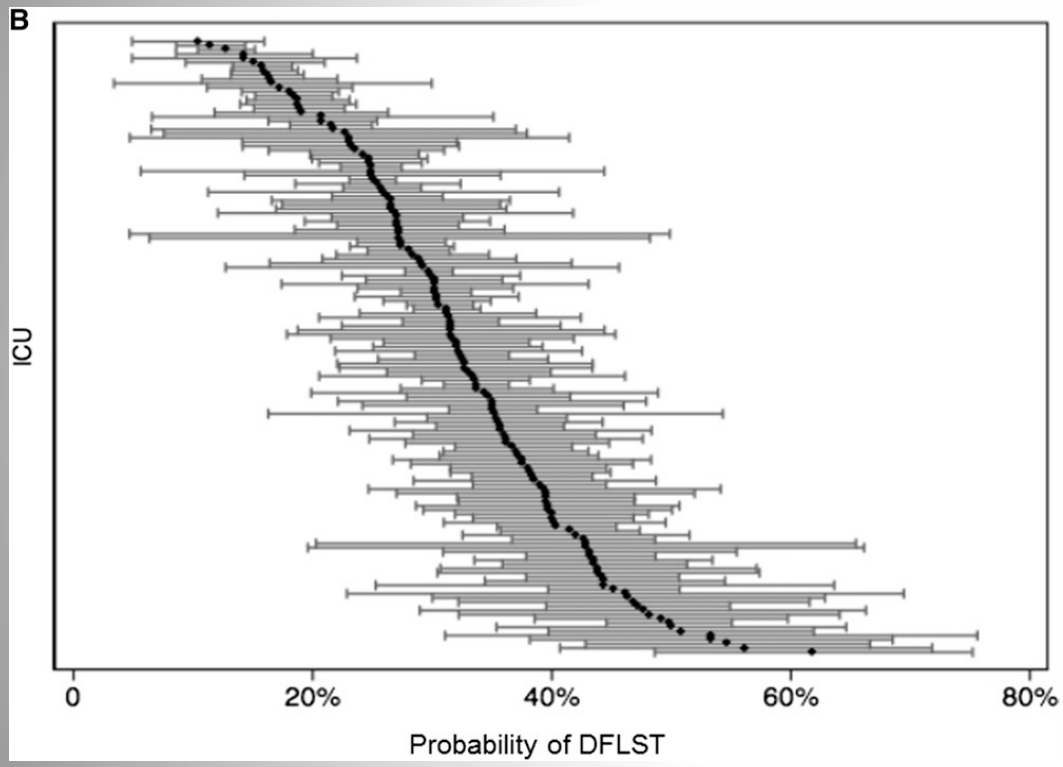
47 (47%) Too Well
Mortality 21.3%

13 (28%) admitted later
8 died - Mortality 61.5%

34 (72%) never admitted
Mortality 6%

J Clin Oncol 2005; 23:4406-4413.

Variability in DFLST



- DFLSTs in 269,002 patients admitted to 153 ICUs in the United States between 2001 and 2009
- Median predicted probability of DFLST among patients requiring PAMV was 32.3
- Range from 12.3% to 61.7%.

CHEST 2014; 146(3): 573 - 582

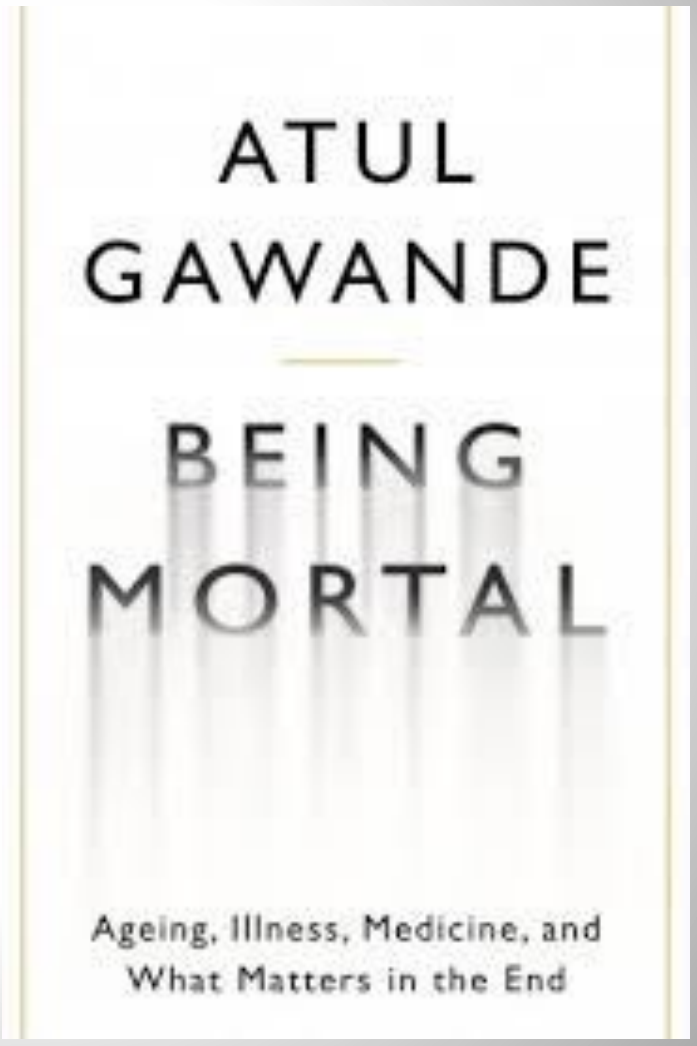
Withdrawal of Mechanical Ventilation in Anticipation of Death in the Intensive Care Unit

Deborah Cook, M.D., Graeme Rocker, D.M., John Marshall, M.D., Peter Sjokvist, M.D., Peter Dodek, M.D., Lauren Griffith, M.Sc., Andreas Freitag, M.D., Joseph Varon, M.D., Christine Bradley, M.D., Mitchell Levy, M.D., Simon Finfer, M.D., Cindy Hamielec, M.D., Joseph McMullin, M.D., Bruce Weaver, B.Sc., Stephen Walter, Ph.D., and Gordon Guyatt, M.D., for the Level of Care Study Investigators and the Canadian Critical Care Trials Group

- 851 patients who were receiving MV
- 17.2% died while receiving MV
- 19.5% had MV withdrawn
- Strongest determinants of withdrawal of MV were

1. **Physician's perception** that the patient preferred not to use life support
2. **Physician's predictions** of a low likelihood of survival
3. **Physician's perception** of high likelihood of poor cognitive function
4. Use of inotropes or vasopressors

N Engl J Med 2003;349:1123-32


ATUL
GAWANDE
BEING
MORTAL
Ageing, Illness, Medicine, and
What Matters in the End

Atul Gawande : Being Mortal

- …well- being is about the reasons one wishes to be alive.
- Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same:
- What is your understanding of the situation and its potential outcomes?
- What are your fears and what are your hopes?
- What are the trade- offs you are willing to make and not willing to make?
- And what is the course of action that best serves this understanding?

Picking a goal of treatment

- Value judgments
- Important nonmedical facts about which physicians also cannot be presumed to be expert
  - completed life projects and is ready to die or
  - has projects yet to accomplish
  - Patients may want to survive to see the birth of grandchildren or
  - even to see relatives arrive for final goodbyes
- Religious concerns

Chest 2015; doi10.1378/chest.15-0275

Against Paternalism

- Lay people should rely on physicians for information about diagnosis, prognosis, and treatment alternatives
- Choosing treatment goals, however, can never be based solely on medical facts
- There is no reason to assume that the physician's beliefs and values are the same as the patient's
- There is no reason to believe that experts medicine are also experts on the value judgments needed to pick a goal.

Chest 2015 doi 10.1378/chest.15-0275

“Doctor, what would you do in my situation?”

- What the physician would want in the patient’s situation has little relevance
- Patient, can be expected to hold different values and confront different nonmedical facts.

Chest 2015 doi 10.1378/chest.15-0275

What about Patients Best Interest?

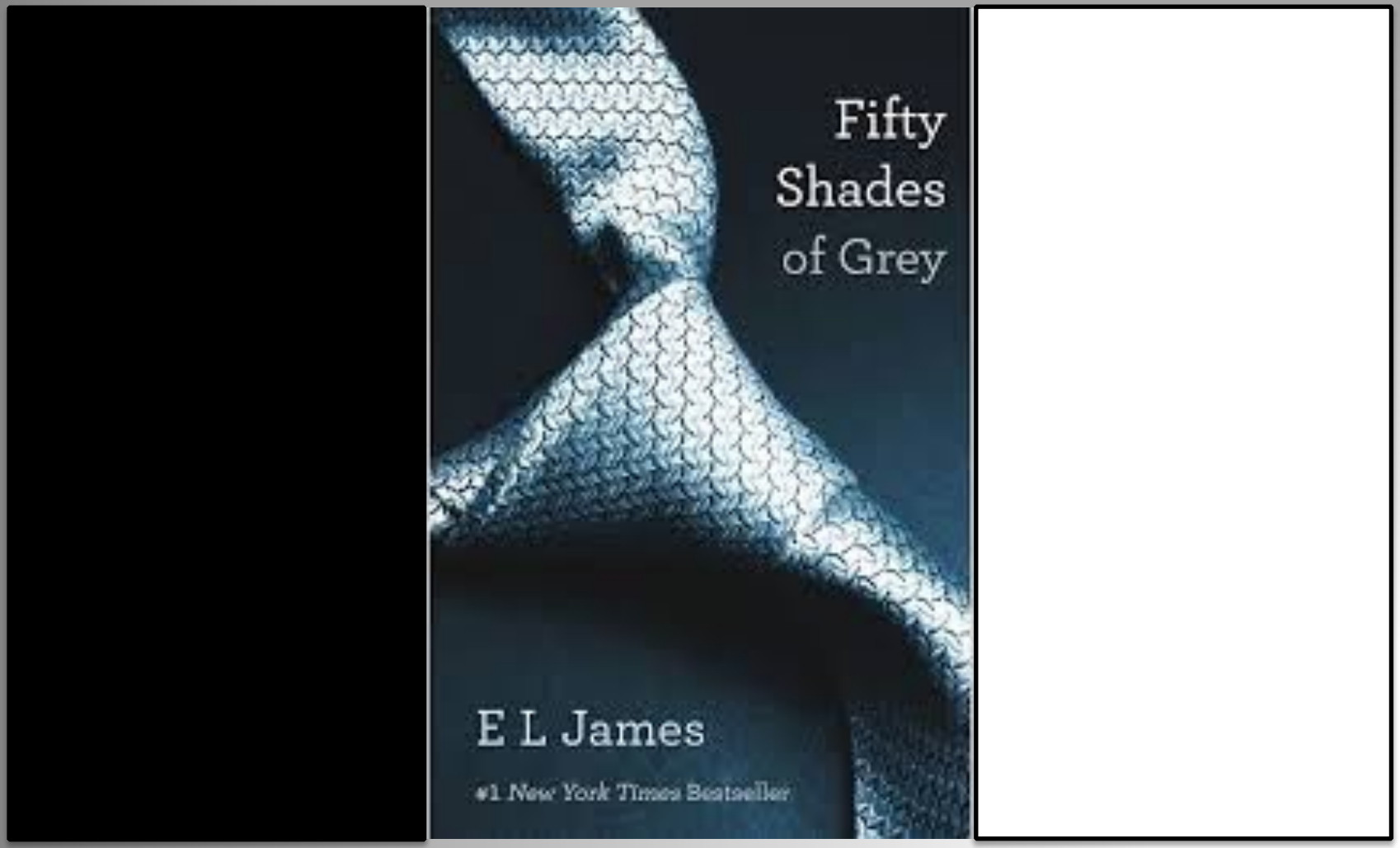
- Patients may rationally not want to pursue their best interest
- People have duties, even if fulfilling them diverges from what is best for the individual
  - Obligations to family
  - To fellow sufferers from the same disease
  - To the next generation.
  - Patients may be duty bound to preserve resources for their children

Chest 2015 doi 10.1378/chest.15-0275

What about Distributive Justice?

- Physicians should be advocates for their patients
- They are not society's sole cost-containment agents
- If recommendations are made to favour societal interests, surrogates must be told this
- If societal interests are to be favoured, is it solely the physician's responsibility?
  - Should other representatives of society have a say?
  - Aren't the surrogates and family part of society?

Decision Making in the ICU
Neither Black nor White



Intensive Care Med (2004) 30:770–784
DOI 10.1007/s00134-004-2241-5

ESICM STATEMENT

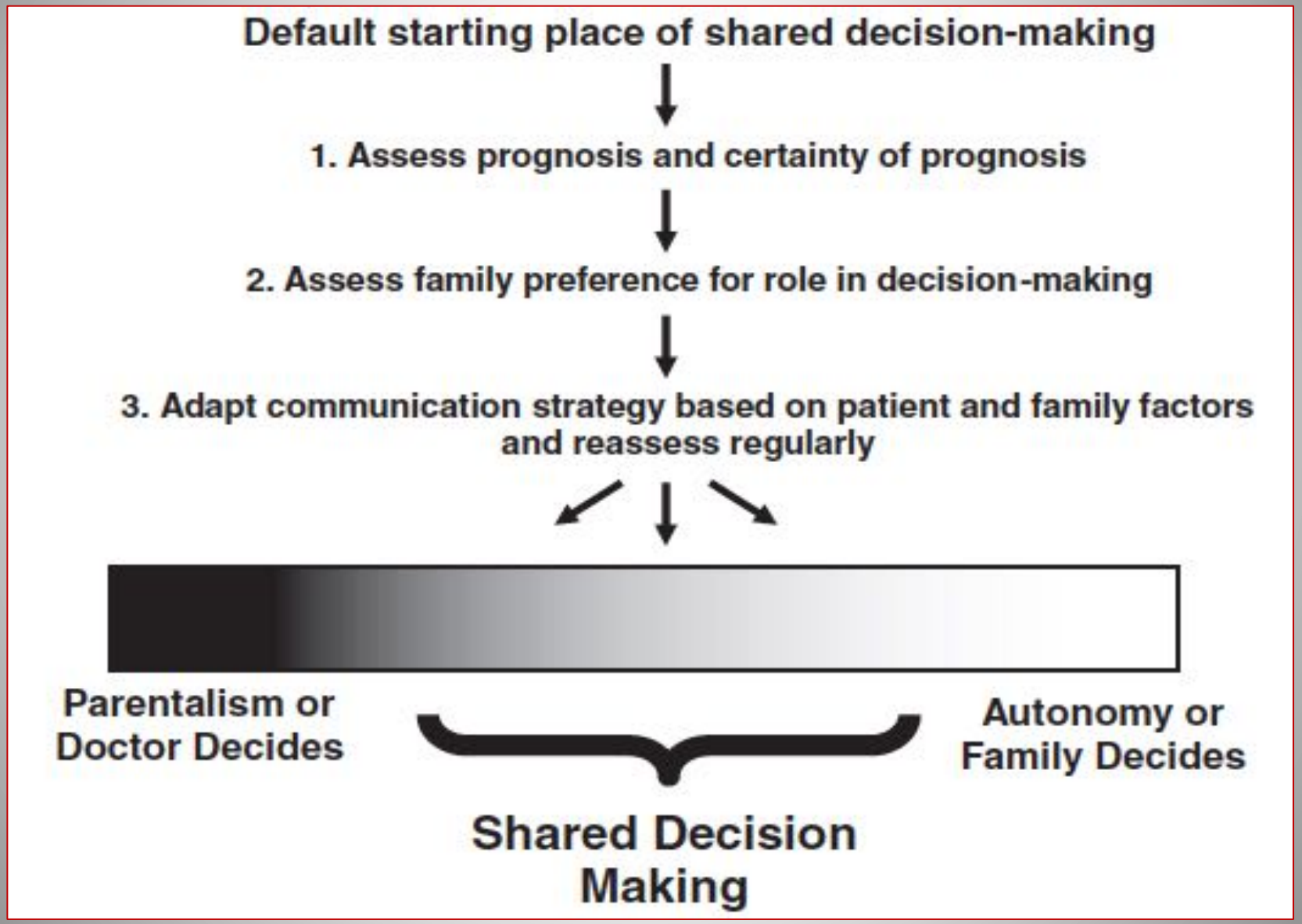
Jean Carlet
Lambertus G. Thijs
Massimo Antonelli
Joan Cassell
Peter Cox
Nicholas Hill
Charles Hinds
Jorge Manuel Pimentel
Konrad Reinhart
Boyd Taylor Thompson

Challenges in end-of-life care in the ICU

Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003

- "Shared" approach to end-of-life decision-making involving the caregiver team and patient surrogates
- Respect for patient autonomy and intention to honour decisions to decline unwanted treatments to be conveyed to the family
- Physician's responsibility to decide on the reasonableness of ction.
- In the event of conflict, continue support for a predetermined time.
- Mechanisms to resolve conflict

Shared Decision Making



CHEST 2008; 134:835–843

AMERICAN THORACIC SOCIETY DOCUMENTS

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

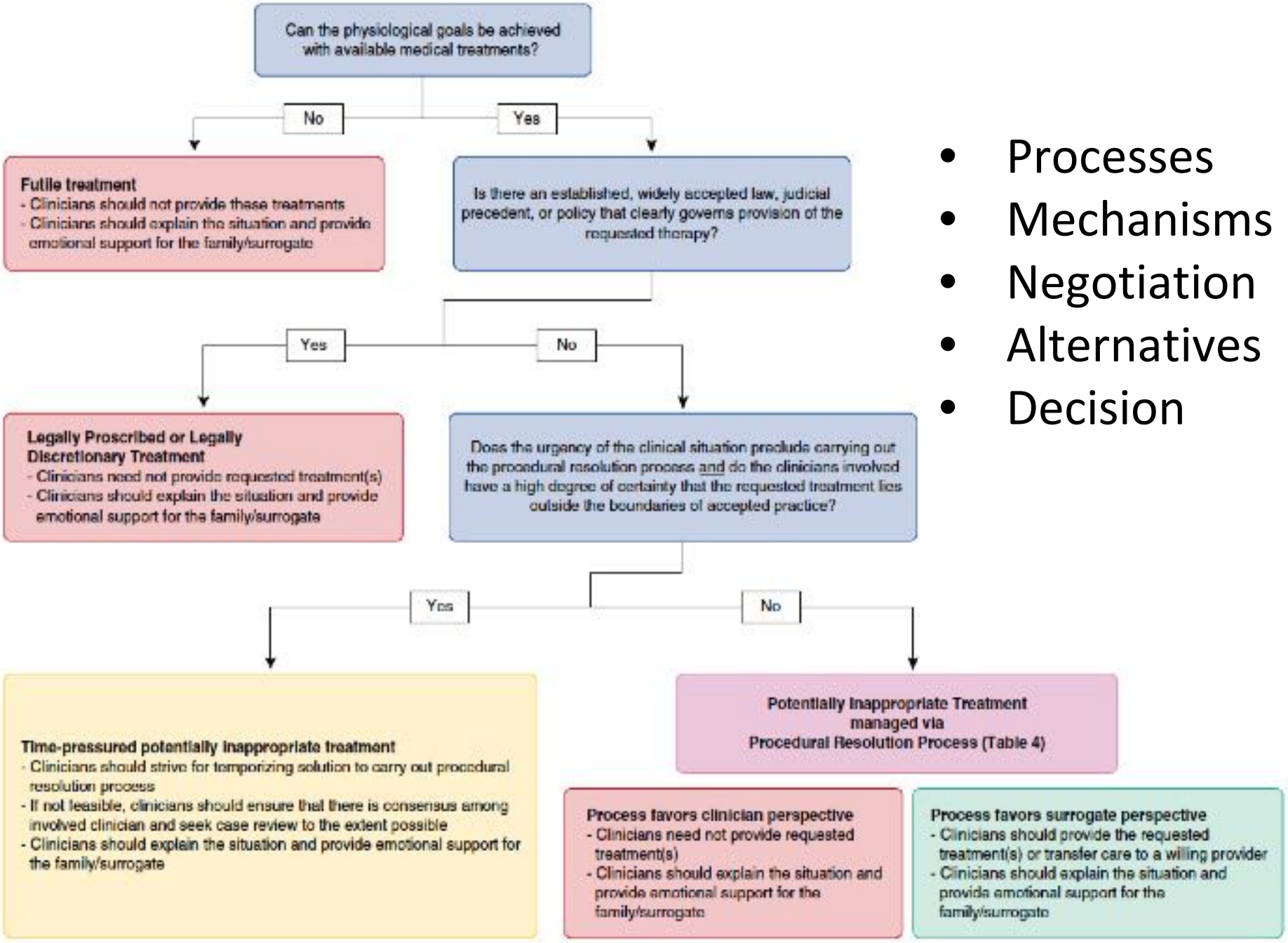
- "potentially inappropriate" should be used, rather than "futile," to describe treatments that
  - have at least some chance of accomplishing the effect sought by the patient
  - but clinicians believe that competing ethical considerations justify not providing them
    - ICU admission for end-stage dementia and MOF
    - Dialysis in a patient in a PVS
    - continue MV in a patient with widely metastatic cancer.
    - Tracheostomy in a child with prolonged respiratory insufficiency and severe irreversible neurological impairment

AJRCCM 2015; 10.1164/rccm.201505-0924ST

Potentially Inappropriate Care

- inappropriate” conveys more clearly than the word “futile” or “ineffective” that the assertion being made by clinicians depends both on technical medical expertise and a value-laden claim, rather than strictly a technical judgment.
- “potentially” signals that the judgments are preliminary, rather than final, and require review before being acted on

AJRCCM 2015; 10.1164/rccm.201505-0924ST



- Processes
- Mechanisms
- Negotiation
- Alternatives
- Decision

AJRCCM 2015; 10.1164/rccm.201505-0924ST

TMH EOLD Study

Number of deaths in ICU (>24 hrs admission)	187
Number of patient in whom EOLC decisions were taken	106 (56.7%)
Males / Females	66 / 40
Age (years)	41 ± 20
Initial APACHE II score	18.4 ± 7.2
APACHE II score at the time of EOLC decision	27.5 ± 8.4
Patients with metastatic cancer	50

End-of-Life Care Process

- Agreement on EOLC was reached between doctors and family after first discussion — 45%
- Agreement on EOLC was reached between doctors and family after two rounds of discussion — 43%
- Agreement on EOLC was reached between doctors and family after three rounds of discussion — 12%
- Family wanted to take the patient home to die — 8%

Dr. RK Mani
Allow Natural Death (AND) Clinic

The Real Problem

- The problem that faces those who put their hope in medical futility as a way to rationalize the provision of care **is not the lack of consensus about a definition**

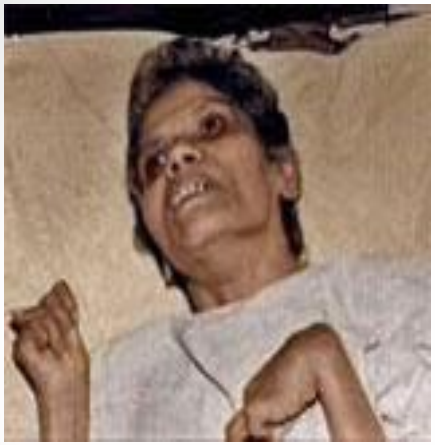
but

- **the absence of trust between physician and patient when it comes to weighing those odds and those ends.**

Ann Intern Med. 1996;125(8):688-689

The Aruna Shanbaug Case

Hospital nurse in PVS for 42 years after attempted strangulation
Cared for by Nurses from the hospital, abandoned by family



Expert Panel Opinion

- If the doctors treating Aruna Shanbaug and the Dean of the KEM Hospital, together acting in the best interest of the patient, feel that withholding or withdrawing life-sustaining treatments is the appropriate course of action, they should be allowed to do so, and their actions should not be considered unlawful.

Aruna Shanbaug Case
Supreme Court of India Judgement 2011

- …Question arises as to who should give consent for withdrawal of life support.
- Considering the low ethical levels prevailing in our society today and the rampant commercialization and corruption, we cannot rule out the possibility that unscrupulous persons with the help of some unscrupulous doctors may fabricate material to show that it is a terminal case with no chance of recovery
- …While many doctors are upright, there are others who can do anything for money

Aruna Shanbaug Case Supreme Court Judgement 2011

- …Hence we have to guard against the potential of misuse
- …. we cannot leave it entirely to their discretion whether to discontinue the life support or not.
- ***Such a decision requires approval from the High Court concerned***
- This is in the interest of the protection of the patient, protection of the doctors, relative and next friend, and for reassurance of the patient's family as well as the public.

AMERICAN THORACIC SOCIETY DOCUMENTS

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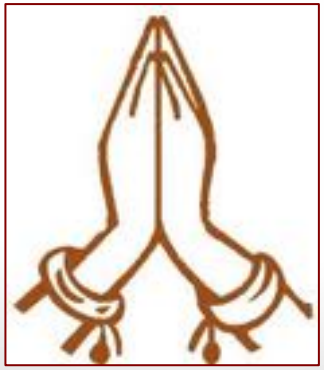
Recommendation 4

- The medical profession should lead public engagement efforts and advocate for policies and legislation about when life-prolonging technologies should not be used.

AJRCCM 2015; 10.1164/rccm.201505-0924ST

관심을 가져 주셔서 감사합니다!



Thank You for your attention!