La ‘vita’ alla fine della vita

Marco Vergano

SIAARTI
PRO VITA CONTRA DOLOREM SEMPER
Gruppo di Studio per la Bioetica

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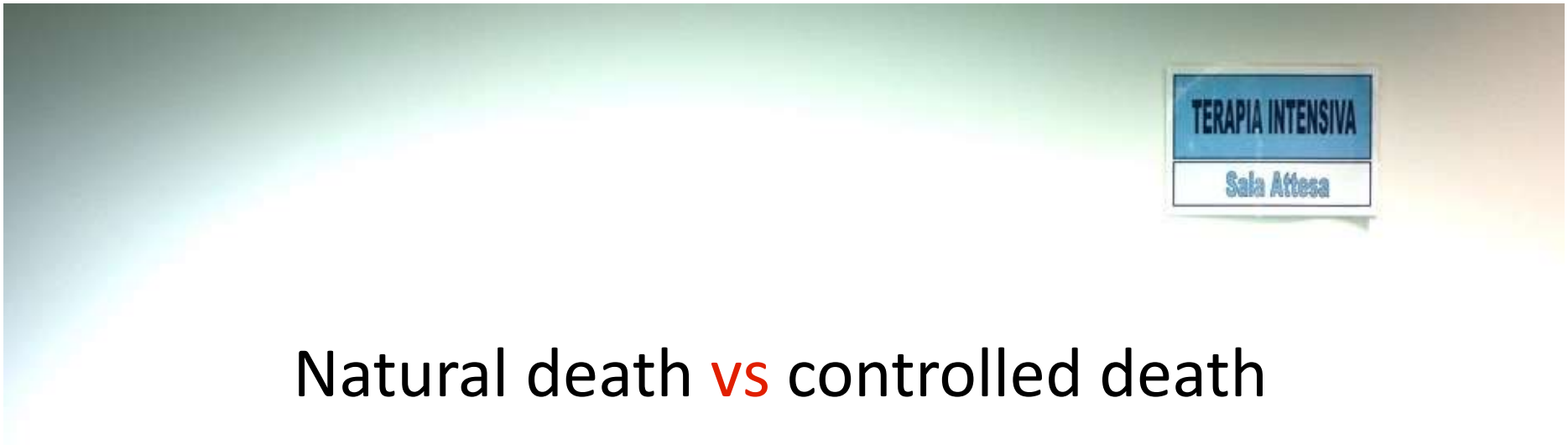
"I'm afraid there's really very little I can do"

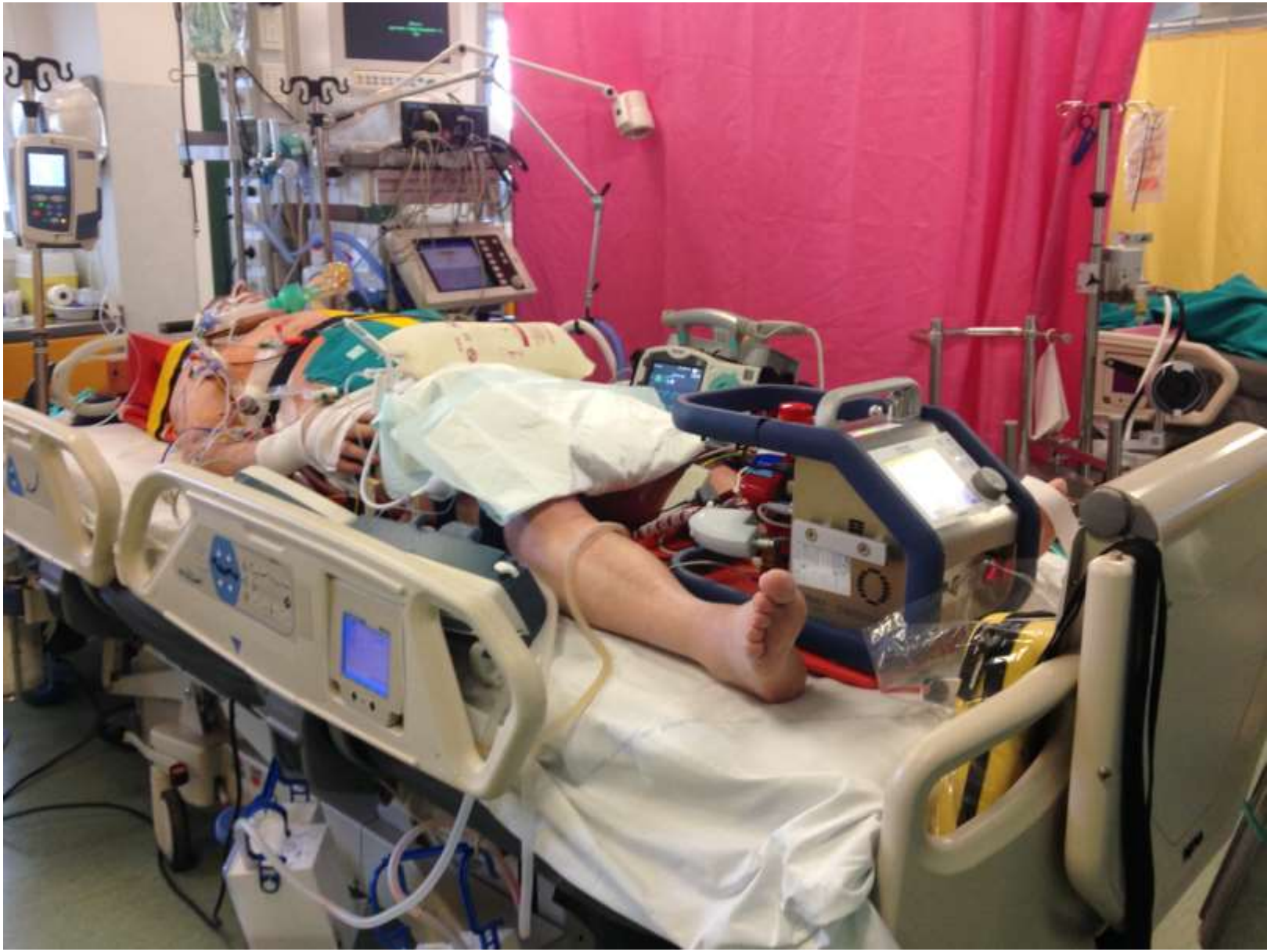
Gahan Allen Wilson (February 18, 1930 – November 21, 2019)

1



Natural death vs controlled death

Luke Flides, *The Doctor*, 1891
Tate Britain, London



ANALYSIS

BMJ 2015;350:h705 doi: 10.1136/bmj.h705 (Published 13 February 2015)

Too much technology

Our abilities to produce and use technologies appear to outrun our abilities to reflect on their application. To avoid becoming technological titans and ethical Lilliputians **Bjørn Morten Hofmann** argues we need a more reflective and responsible implementation of health technology

Bjørn Morten Hofmann *researcher*[1 2 3]

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«technological titans and ethical Lilliputians»

Should doctors be doing all the things they are doing?

HTM: High Tecnology Medicine

biology ≠ biography

chronic critical illness

La **medicina** ha infatti sviluppato una sempre **maggiore capacità terapeutica**, che ha permesso di sconfiggere molte malattie, di migliorare la salute e **prolungare il tempo della vita**.

Essa ha dunque svolto un ruolo molto positivo. D'altra parte, oggi è anche possibile **protrarre la vita** in condizioni che in passato non si potevano neanche immaginare.

Gli interventi sul corpo umano diventano sempre più efficaci, ma non sempre sono risolutivi: possono sostenere funzioni biologiche divenute insufficienti, o addirittura sostituirle, ma questo **non equivale a promuovere la salute**.

Occorre quindi un **supplemento di saggezza**, perché oggi è più insidiosa la tentazione di insistere con trattamenti che producono potenti effetti sul corpo, ma talora **non giovano al bene integrale della persona**.

La Santa Sede

MESSAGGIO DEL SANTO PADRE FRANCESCO AI PARTECIPANTI AL MEETING REGIONALE EUROPEO DELLA "WORLD MEDICAL ASSOCIATION" SULLE QUESTIONI DEL "FINE-VITA"

[Vaticano, Aula Vecchia del Sinodo, 16-17 novembre 2017]

Il Papa Pio XII, in un memorabile discorso rivolto 60 anni fa ad anestesisti e rianimatori, affermò che **non c'è obbligo** di impiegare sempre tutti i mezzi terapeutici potenzialmente disponibili e che, in casi ben determinati, è lecito astenersene (cfr Acta Apostolicae Sedis XLIX [1957],1027-1033).

È dunque **moralmente lecito rinunciare all'applicazione di mezzi terapeutici, o sospenderli**, quando il loro impiego non corrisponde a quel criterio etico e umanistico che verrà in seguito definito "**proporzionalità delle cure**" […]

Consente quindi di giungere a una decisione che si qualifica moralmente come **rinuncia all'"accanimento terapeutico".**
È una scelta che assume responsabilmente **il limite della condizione umana mortale**, nel momento in cui prende atto di non poterlo più contrastare.

2

Bioethical Inquiry (2011) 8:123–131
DOI 10.1007/s11673-011-9293-3

Defining Medical Futility and Improving Medical Care

Lawrence J. Schneiderman

la probabilità inaccettabile di ottenere un ***effetto***
che il paziente possa apprezzare come un ***beneficio***

Trends in Anaesthesia and Critical Care 4 (2014) 167–169

Contents lists available at ScienceDirect

Trends in Anaesthesia and Critical Care

journal homepage: www.elsevier.com/locate/tacc

REVIEW

Futility in medicine

Marco Vergano [a], Giuseppe Renato Gristina [b, *]

[a] Anesthesia Department and ICU, S. Giovanni Bosco Hospital, Turin, Italy
[b] Study Group on Bioethics, Italian Society of Anaesthesia and Intensive Care Medicine, Italy

Table 1
Futility: main meanings used in clinical practice.

Type of futility	Referred to	Author, year
Qualitative	Extremely poor quality of the effect produced by the occurrence of the event	Schneiderman, 1996
Quantitative	The extreme unlikelihood of the success of an event	Schneiderman, 1996
Value futility	Our intervention obtains an effect, but this doesn't produce any benefit	Mohindra, 2007
Goal futility	Our intervention doesn't alter the course of events	Mohindra, 2007

"Those who call for the abandonment of the concept have no substitute to offer. They persist in making decisions with, more or less, covert definitions.

The common sense notion that **a time does come for all of us when death or disability exceeds our medical powers** cannot be denied. This means that **some operative way of making a decision when 'enough is enough' is necessary**.

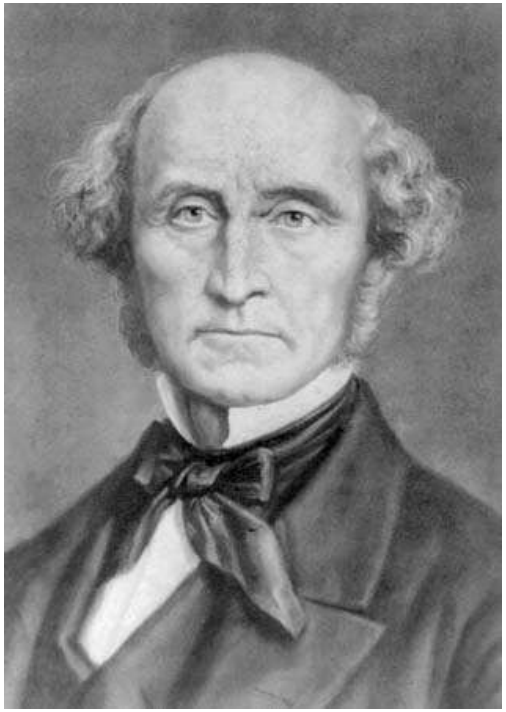
It is a mark of our mortality that we shall die. For each of us some determination of futility by any other name will become a reality"

Pellegrino, E.D. 2005. Decisions at the end of life—the abuse of the concept of futility. Practical Bioethics 1(3): 3–6

3

"Over himself, over his own body and mind, the individual is sovereign"

John Stuart Mill, *On Liberty*, 1859



"No decisions about me without me"

Art. 13 e 32 della Costituzione,
Codice di Deontologia Medica,
Codice Deontologico degli Infermieri,
Convenzione di Oviedo,
Consiglio d'Europa,
Raccomandazioni SIAARTI e SICP,
Legge 219/2017*…*

MAKING SHARED DECISION-MAKING A REALITY

No decision about me, without me

Angela Coulter, Alf Collins

The King's Fund

Foundation for Informed Medical Decision Making

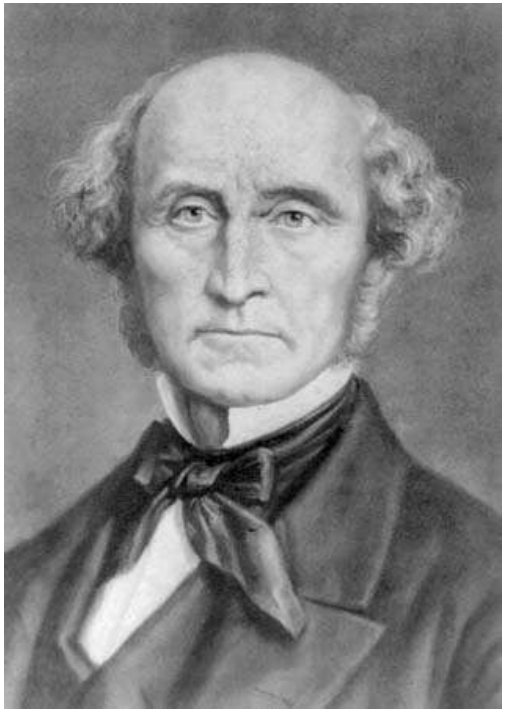
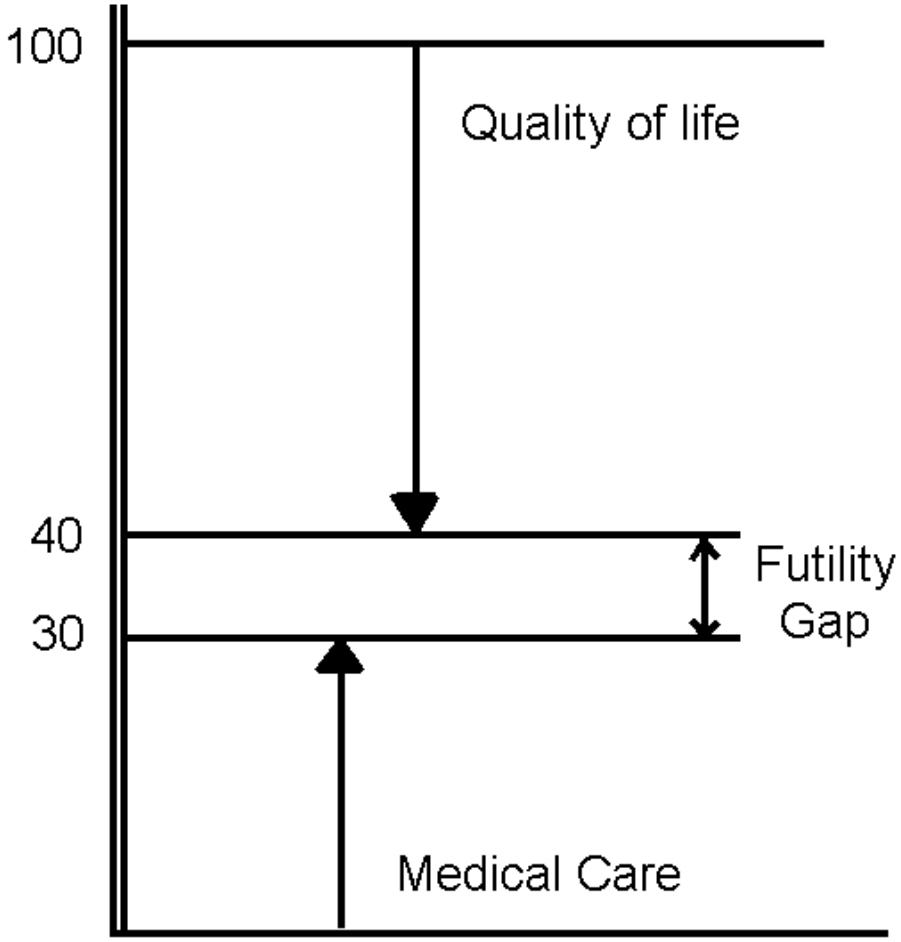
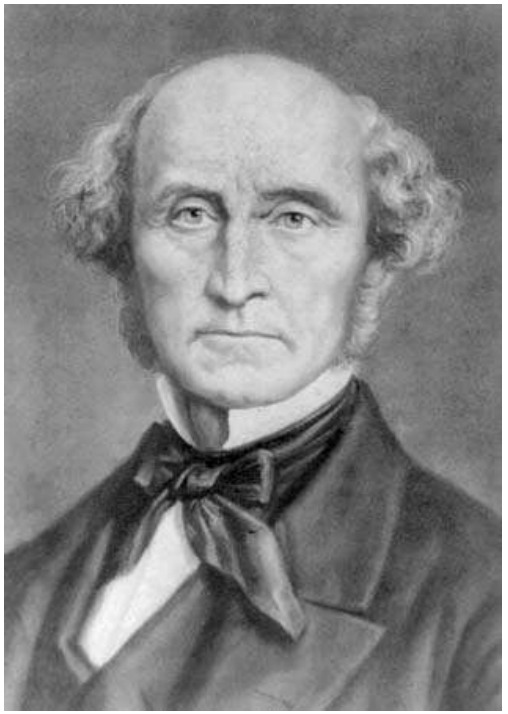


Table 1 Sharing expertise

Clinician's expertise	Patient's expertise
Diagnosis	Experience of illness
Disease aetiology	Social circumstances
Prognosis	Attitude to risk
Treatment options	Values
Outcome probabilities	Preferences

futility gap





J. Civetta, 1996

Life after intensive care: it's life…
…but not as we know it!

Cuthbertson *et al. Critical Care* 2010, **14**:R6
http://ccforum.com/content/14/1/R6

CRITICAL CARE

RESEARCH Open Access

Quality of life in the five years after intensive care: a cohort study

Brian H Cuthbertson[1*], Siân Roughton[2], David Jenkinson[3], Graeme MacLennan[3], Luke Vale[2,4]

Abstract

Introduction: Data on quality of life beyond 2 years after intensive care discharge are limited and we aimed to explore this area further. Our objective was to quantify quality of life and health utilities in the 5 years after intensive care discharge.

Methods: A prospective longitudinal cohort study in a University Hospital in the UK. Quality of life was assessed from the period before ICU admission until 5 years and quality adjusted life years calculated.

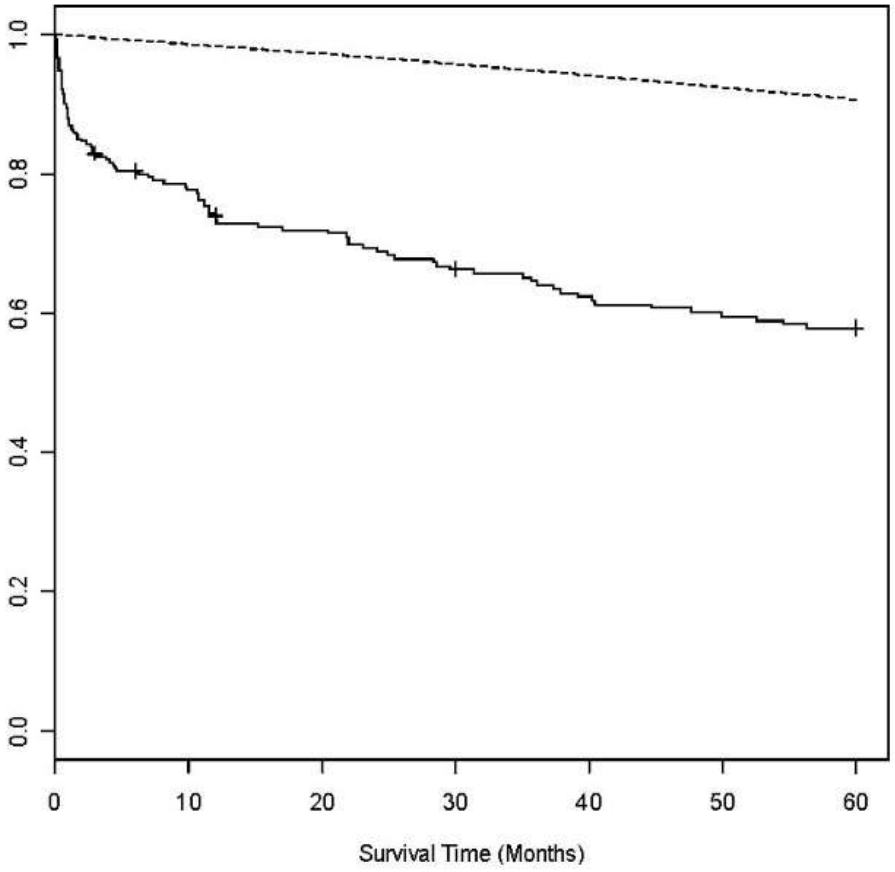
Results: 300 level 3 intensive care patients of median age 60.5 years and median length of stay 6.7 days, were recruited. Physical quality of life fell to 3 months ($P = 0.003$), rose back to pre-morbid levels at 12 months then fell again from 2.5 to 5 years after intensive care ($P = 0.002$). Mean physical scores were below the population norm at all time points but the mean mental scores after 6 months were similar to those population norms. The utility value measured using the EuroQOL-5D quality of life assessment tool (EQ-5D) at 5 years was 0.677. During the five years after intensive care unit, the cumulative quality adjusted life years were significantly lower than that expected for the general population ($P < 0.001$).

Conclusions: Intensive care unit admission is associated with a high mortality, a poor physical quality of life and a low quality adjusted life years gained compared to the general population for 5 years after discharge. In this group, critical illness associated with ICU admission should be treated as a life time diagnosis with associated excess mortality, morbidity and the requirement for ongoing health care support.

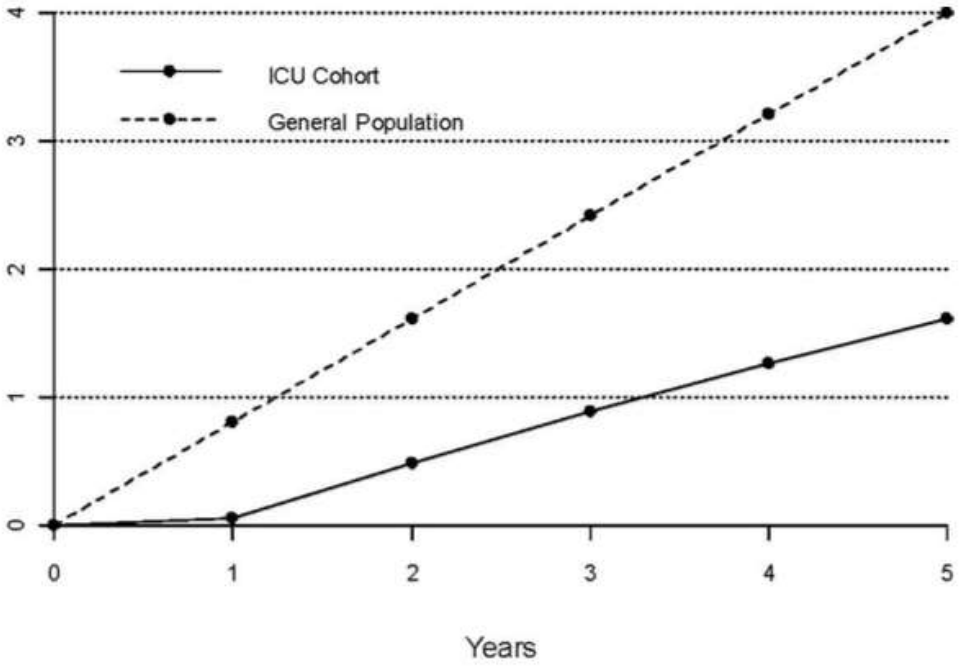
critical illness with ICU admission = **life time diagnosis** with excess mortality & morbidity

survival after ICU

cumulative survival



cumulative QALYs



Cuthbertson *et al. Critical Care* 2010, **14**:R6
http://ccforum.com/content/14/1/R6

4

Intensive Care Med (2010) 36:1495–1504
DOI 10.1007/s00134-010-1910-9

ORIGINAL

Guido Bertolini
Simona Boffelli
Paolo Malacarne
Mario Peta
Mariano Marchesi
Camillo Barbisan
Stefano Tomelleri
Simonetta Spada
Roberto Satolli
Bruno Gridelli
Ivo Lizzola
Davide Mazzon

End-of-life decision-making and quality of ICU performance: an observational study in 84 Italian units

Patient consent to the course of treatment

On ICU admission, 546 patients (**14.4%**) were judged **able to express informed consent** to the course of treatment, but only 307 (**8.1%** of the total) were **actually involved in the plan of care**.

Il paziente è il grande assente!

VIEWPOINT Open Access

New perspectives on substituted relational autonomy for shared decision-making in critical care

Nicola Grignoli[1,2,3*], Valentina Di Bernardo[1,2,4] and Roberto Malacrida[1]

Critical Care

Grignoli *et al. Critical Care* (2018) 22:260
https://doi.org/10.1186/s13054-018-2187-6

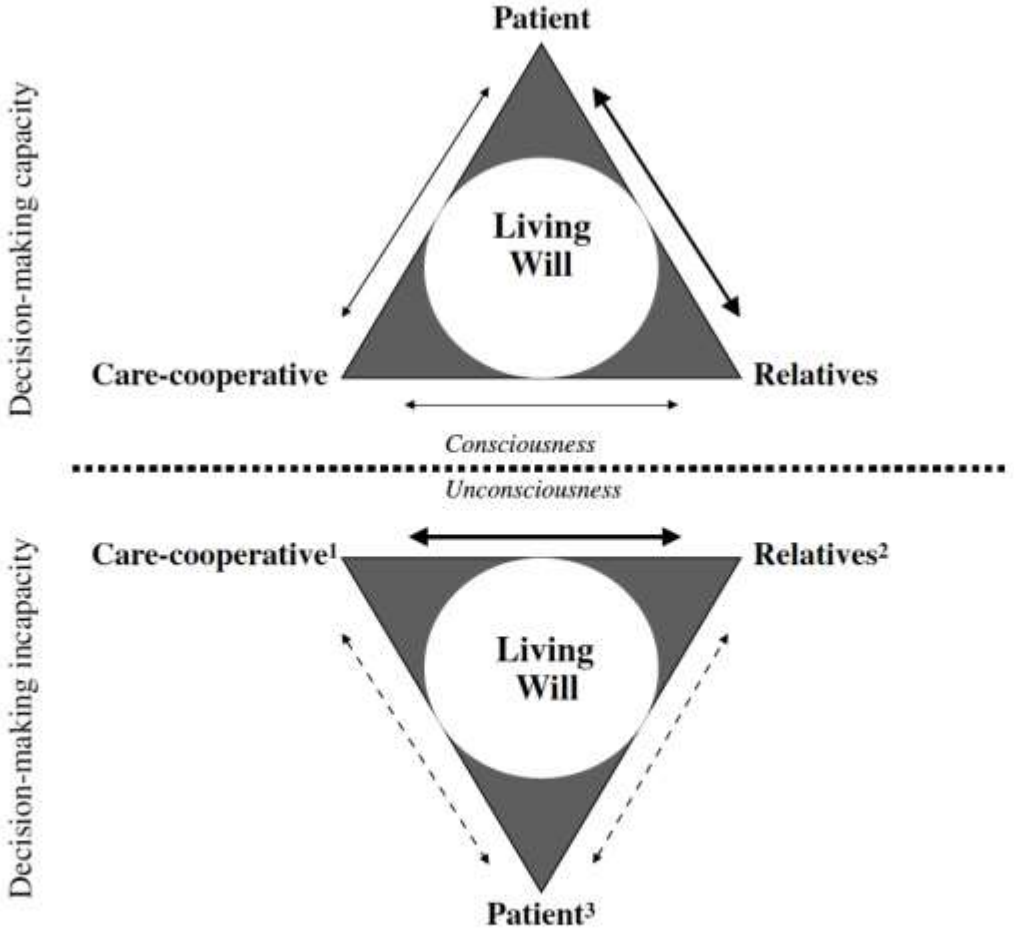


Fig. 1 The substitute relational autonomy model for SDM in critical care. *1* Previous discussion with patients of therapeutic procedures, clinical team-shared opinion. *2* Knowledge of patients' health-related quality of life, character and will to live (demonstrated resilience), history of illness. *3* Advanced directives, previous opinions, non-verbal communication. Narrowing represents communication links between parties involved in SDM in critical care

VIEWPOINT Open Access

New perspectives on substituted relational autonomy for shared decision-making in critical care

Nicola Grignoli[1,2,3*], Valentina Di Bernardo[1,2,4] and Roberto Malacrida[1]

Critical Care

Grignoli *et al. Critical Care* (2018) 22:260
https://doi.org/10.1186/s13054-018-2187-6

Fig. 2 Moonlight as an illustration of substituted relational autonomy in critical care. Taking the earth as the individual and its satellite the moon as the relative, moonlight can be seen as what can still shed light on a living will during the night of an unconscious state

5

Prediction Is Very Difficult, Especially About the Future*

Nicola Latronico, MD
Department of Anesthesia and Critical Care Medicine
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DOI: 10.1097/CCM.0000000000000795

Critical Care Medicine

February 2015 • Volume 43 • Number 2

"Is the outcome of critically ill patients inherently **unpredictable**? Yes, if early prediction of **individual outcome** is at stake."

"We should concentrate on the **consequences** of critical illness, which can be known, rather than on the **probability** that they will occur, which can't."

prognostic uncertainty

[Original Research **Critical Care**]

CHEST

CHEST 2014; 146(2):267-275

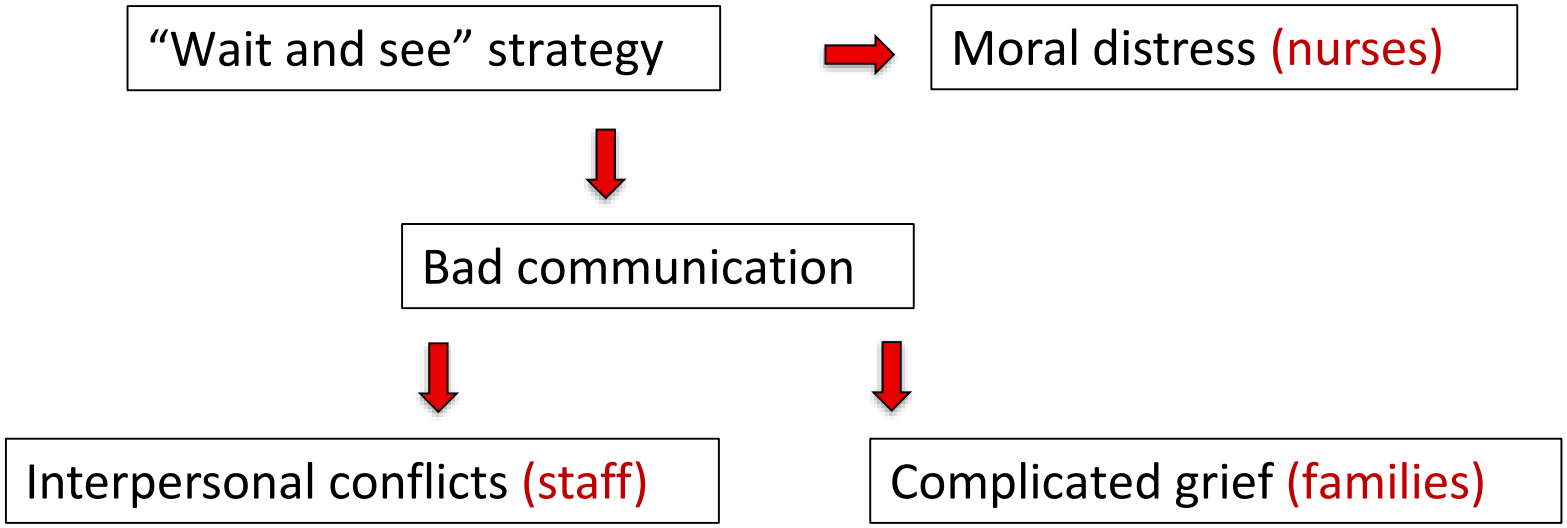
Inappropriate Care in European ICUs

Confronting Views From Nurses and Junior and Senior Physicians

Ruth D. Piers, MD, PhD; Elie Azoulay, MD, PhD; Bara Ricou, MD; Freda DeKeyser Ganz, RN, PhD; Adeline Max, MD; Andrej Michalsen, MD, MPH; Paulo Azevedo Maia, MD; Radoslaw Owczuk, MD, PhD; Francesca Rubulotta, MD, PhD; Anne-Pascale Meert, MD; Anna K. Reyners, MD, PhD; Johan Decruyenaere, MD, PhD; and Dominique D. Benoit, MD, PhD; for the Appropricus Study Group of the Ethics Section of the European Society of Intensive Care Medicine

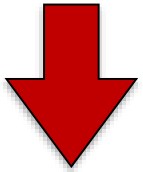
The most commonly reported reason for **disproportionate care** was **prognostic uncertainty**, reflecting the well known difficulties raised by mortality prediction in ICU patients

Many physicians, as shown in this study, thus seem to retreat to the world of “prognostic uncertainty,” in which everything remains possible, so that **waiting seems the best and safest option**

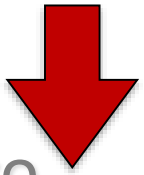


«Systematically using this "wait and see" strategy is **inadequate** and even **harmful**;
however, when there are good reasons to postpone decisions, **better communication of the prognostic uncertainty** to the team and the families is warranted»

incertezza prognostica



paralisi prognostica/decisionale



accanimento terapeutico

ostinazione irragionevole

The conveyor belt (il nastro trasportatore):

It is common for those with an **acute illness**, in the context of **severe frailty** to be taken to a hospital, resuscitated in the emergency room and admitted to an ICU.

It is difficult for anyone to confront these pressures, to **stand back**, to honestly explain the situation to the patient and caregivers and to **pluck the person off the conveyor belt**.

Hillman et al, Intensive Care Med (2015) 41:1700–1702

BECOMING A PHYSICIAN

Tolerating Uncertainty — The Next Medical Revolution?

Arabella L. Simpkin, B.M., B.Ch., M.M.Sc, and Richard M. Schwartzstein, M.D.

"Our need to **tolerate uncertainty** has never been more urgent"

"Doctors continually have to **make decisions** on the basis of **imperfect data** and **limited knowledge**, which leads to **diagnostic uncertainty**, coupled with the uncertainty that arises from **unpredictable patient responses** to treatment and from health care outcomes that are far from binary."

Black and white decisions → **"gray zone"**

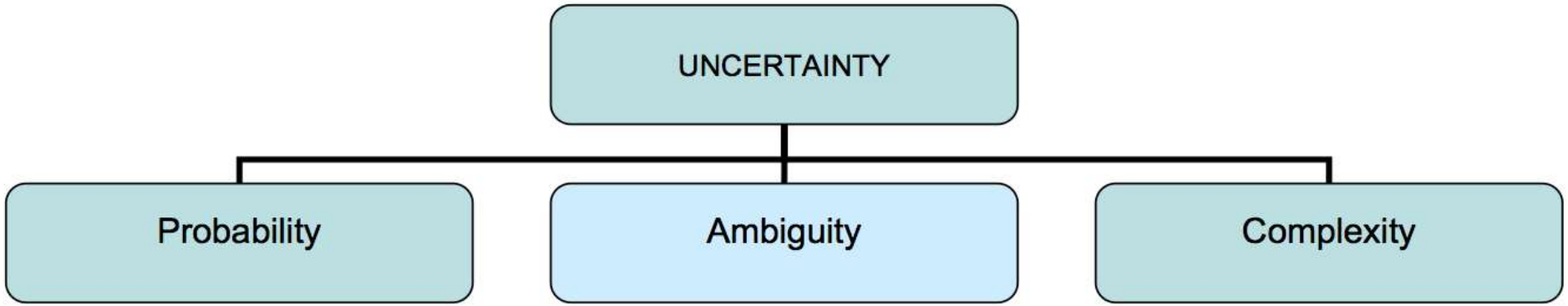
N ENGL J MED 375;18 NEJM.ORG NOVEMBER 3, 2016

6

Varieties of Uncertainty in Health Care: A Conceptual Taxonomy

Paul K. J. Han, MD, MA, MPH, William M. P. Klein, PhD, Neeraj K. Arora, PhD

(Med Decis Making 2011;31:828-838)



20% probability of benefit from treatment *(indeterminacy of future outcome)*

10-30% probability of benefit from treatment *(imprecision)*

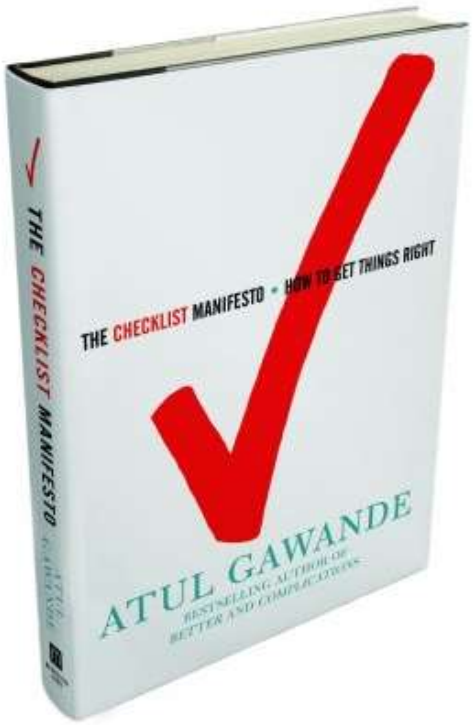
Expert disagreement about benefits *(conflicting opinion/evidence)*

Insufficient scientific evidence of benefit *(lack of information)*

20% probability of ICU survival in patients with septic shock and MOF, with more than 2 comorbidities at admission*

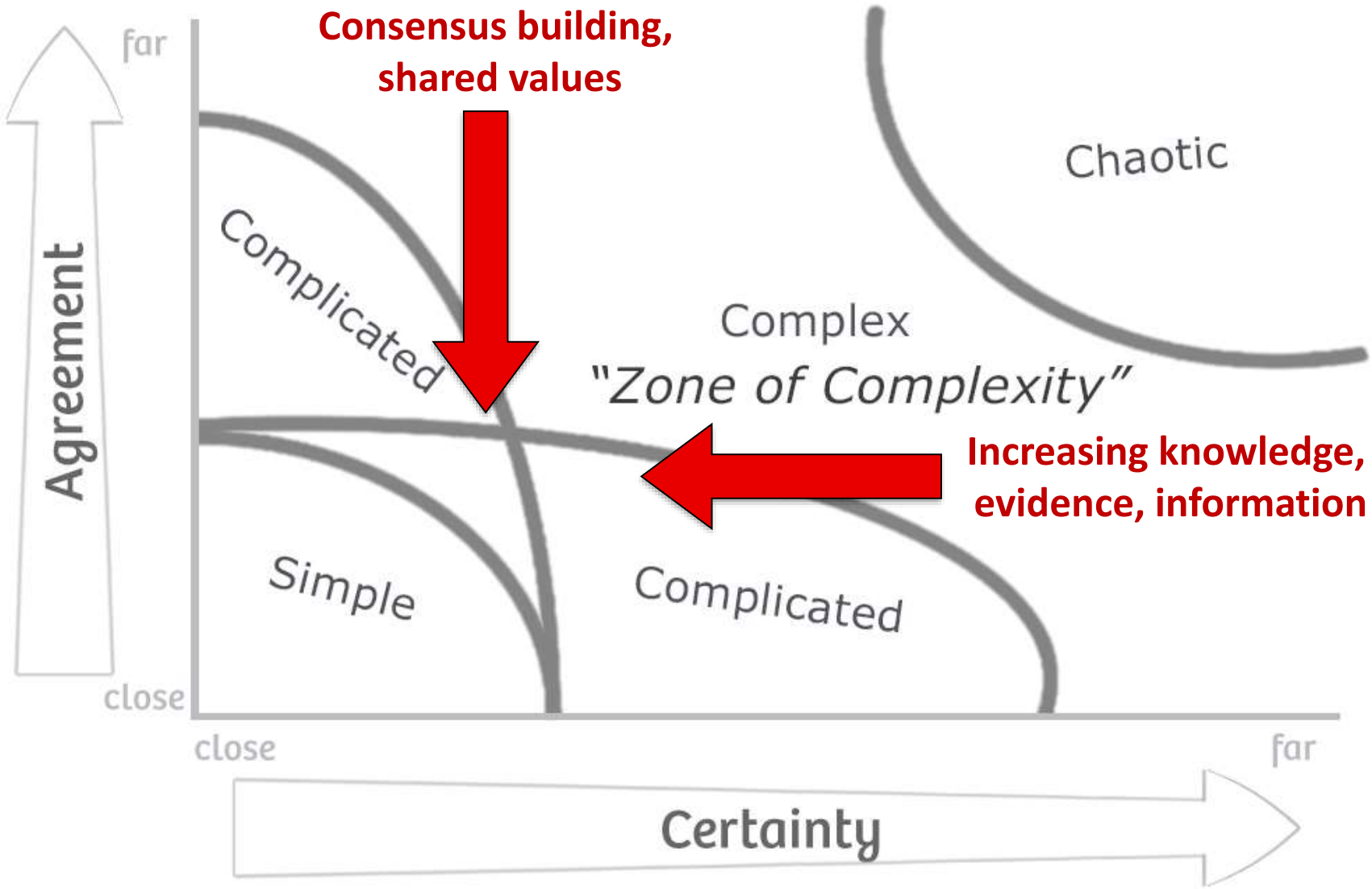
(multiplicity of causal factors and interpretative cues)

*modified from original



“Ci sono problemi **semplici** (preparare un dolce seguendo una ricetta), **complicati** (mandare in aria un razzo) e **complessi** (crescere un figlio)”

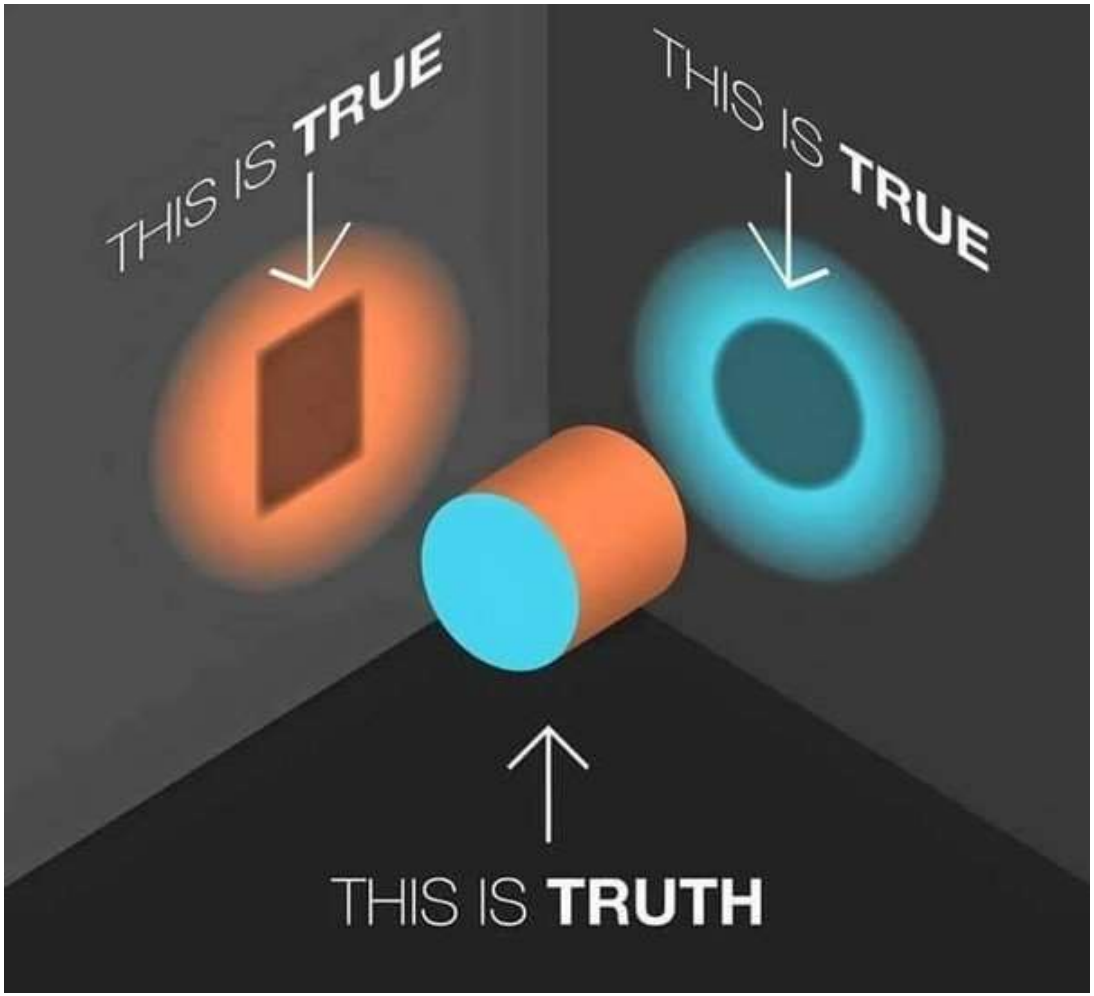
simple	complicated	complex
Following a recipe	A rocket to the moon	Raising a child
• The recipe is essential • Recipes are tested to assure replicability on later efforts • No particular expertise (knowing how to cook increases success) • Recipes produce standard products • **Certainty of same results every time**	• Expertise is necessary • Sending one rocket increases assurance that next will be ok • High level of specialization + coordination • Rockets similar in critical ways • **High certainty of outcome**	• Expertise is not enough • Raising one child gives no assurance of success with the next • Coordination is not enough • Every child is unique • **Uncertainty of outcomes remains**

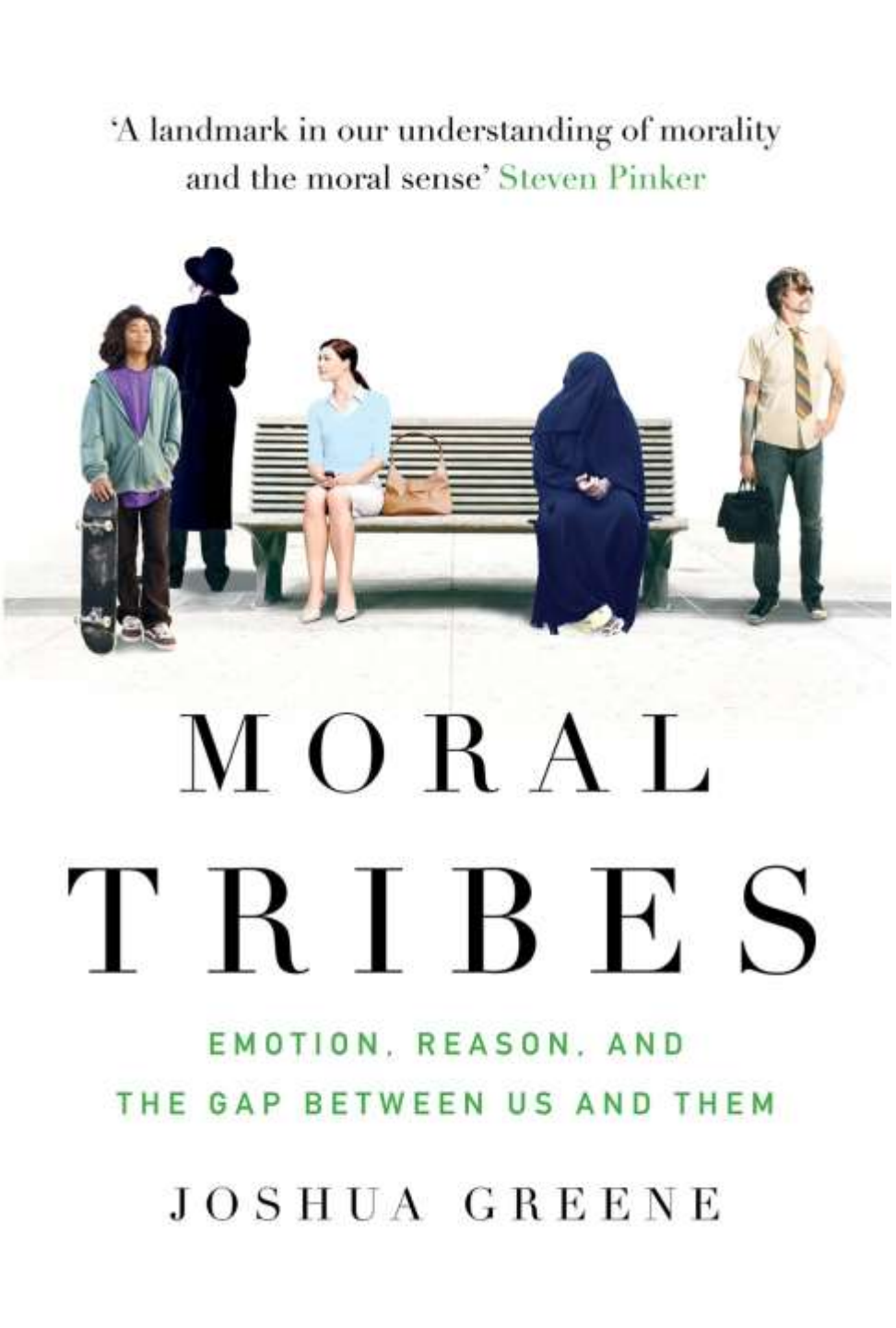

Consensus building,
shared values
far
Agreement
close
Chaotic
Complicated
Complex
"Zone of Complexity"
Increasing knowledge,
evidence, information
Simple
Complicated
close
far
Certainty

7

«Ciascuno prende i limiti del suo campo visivo per i confini del mondo»

(Arthur Schopenhauer)





me versus **us**

us versus **them**

bioethics

Bioethics ISSN 0269-9702 (print); 1467-8519 (online)
Volume 30 Number 2 2016 pp 109–118

doi:10.1111/bioe.12162

IN FAVOUR OF MEDICAL DISSENSUS: WHY WE SHOULD AGREE TO DISAGREE ABOUT END-OF-LIFE DECISIONS

DOMINIC WILKINSON, ROBERT TRUOG AND JULIAN SAVULESCU

The process of **reasoned discussion**, elucidation of **facts**, and exploration of **values** is worthwhile even if agreement is not forthcoming.

End-of-life decisions are, by their nature, difficult, unsettling and sometimes distressing.
Professionals, understandably, have **different views** about them, and will sometimes reach **different conclusions**.
However, such **disagreement** is not necessarily a sign that we are on the wrong track, and should not be taken to preclude withholding or withdrawing treatment if that is consistent with thepatient's/family's wishes.

Let's agree to disagree!

8

VIEWPOINT

Toward Better ICU Use at the End of Life

Derek C. Angus, MD, MPH
Department of Critical Care Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania; and Associate Editor, *JAMA*.

Robert D. Truog, MD
Center for Bioethics, Harvard Medical School, Boston, Massachusetts.

5 strategie per migliorare

- ridurre le ammissioni inappropriate in TI
- rivalutare gli obiettivi di cura durante il ricovero
- implementare un processo di decisioni condivise con pazienti e familiari
- aumentare la condivisione delle scelte all'interno di tutta l'equipe dei curanti
- rendere le Terapie Intensive **più umane**

JAMA January 19, 2016 Volume 315, Number 3

The NEW ENGLAND JOURNAL of MEDICINE

REVIEW ARTICLE

CRITICAL CARE MEDICINE

Simon R. Finfer, M.D., and Jean-Louis Vincent, M.D., Ph.D., *Editors*

Dying with Dignity in the Intensive Care Unit

Deborah Cook, M.D., and Graeme Rocker, D.M.

ON THE NEED FOR PALLIATIVE CARE

The coexistence of palliative care and critical care may seem paradoxical in the technological ICU. However, contemporary critical care should be as concerned with palliation as with the prevention, diagnosis, monitoring, and treatment of life-threatening conditions.

in sintesi:

- è la capacità di «**insistenza**» terapeutica ad aver reso necessaria la riflessione sulla «**desistenza**»
- la desistenza terapeutica – nelle condizioni in cui è **giustificata** – è buona pratica clinica
- non vi è distinzione sul piano etico tra ***withholding*** (astensione) e ***withdrawing*** (sospensione)
- la proporzione di pazienti che muoiono dopo limitazione delle cure è in crescita, seppur con notevole **disomogeneità**
- la sospensione delle terapie deve essere accompagnata da **sedazione palliativa**/terminale
- gli atti di desistenza terapeutica devono seguire un **protocollo** ed essere accuratamente **documentati**
- la comunicazione (tra operatori e con i pazienti/familiari) è essenziale e va implementata: la comunicazione è tempo di cura!

«The technical and moral aspects of patient care are inseparable»

Albert R. Jonsen

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