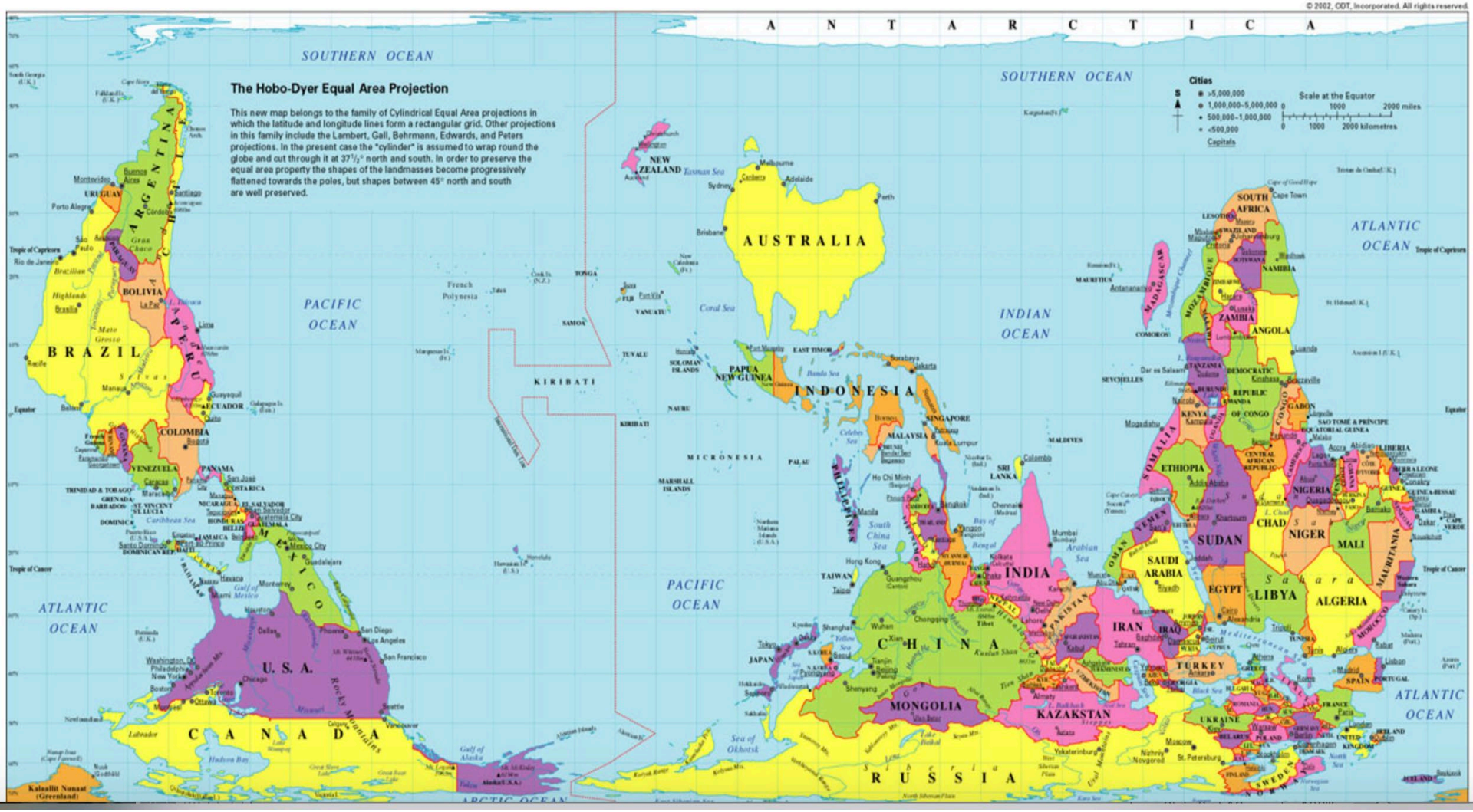
Dying in the 21st Century
What choices do we have?

Peter Saul

Australia



Darwin to Perth	4396km
Perth to Adelaide	2706km
Adelaide to Melbourne	726km
Melbourne to Sydney	887km
Sydney to Brisbane	972km
Brisbane to Cairns	1748km

Darwin
Cairns
Broome
Eire
UK
Townsville
Germany
Poland
France
Czech
Austria
Hungary
Romania
Fraser Island
Noosa
Brisbane
Portugal
Spain
Italy
Yugoslavia
Bulgaria
Perth
Adelaide
Greece
Sydney
Canberra
Melbourne
Hobart

Area size comparision of

Australia and Europe

Australia's area = 7,706,168 sq km

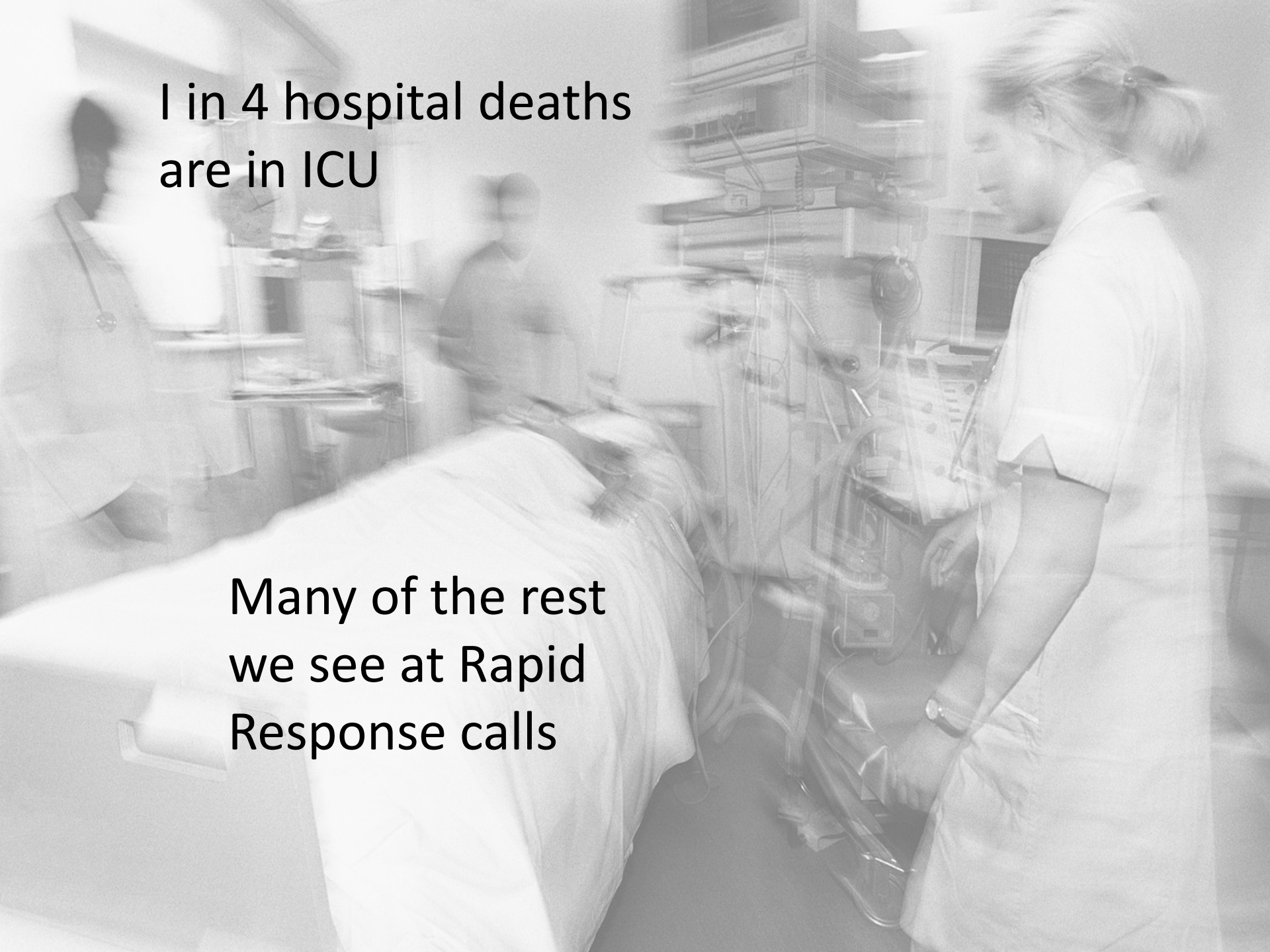
Europe's area as shown = 3.483,066 sq km


Banda Sea
Papua New Guinea
Arafura Sea
Solomon Sea
Timor Sea
NORTHERN TERRITORY
Coral Sea
QUEENSLAND
Australia
WESTERN AUSTRALIA
Brisbane
SOUTH AUSTRALIA
Perth
NEW SOUTH WALES
Newcastle
Adelaide
Sydney
Great Australian Bight
ACT
VICTORIA
Melbourne
Tasman Sea
TASMANIA


Daniel Rankmore


VH-ZXC
RESCUE
NSWAmbulance
RESCUE


I in 4 hospital deaths
are in ICU

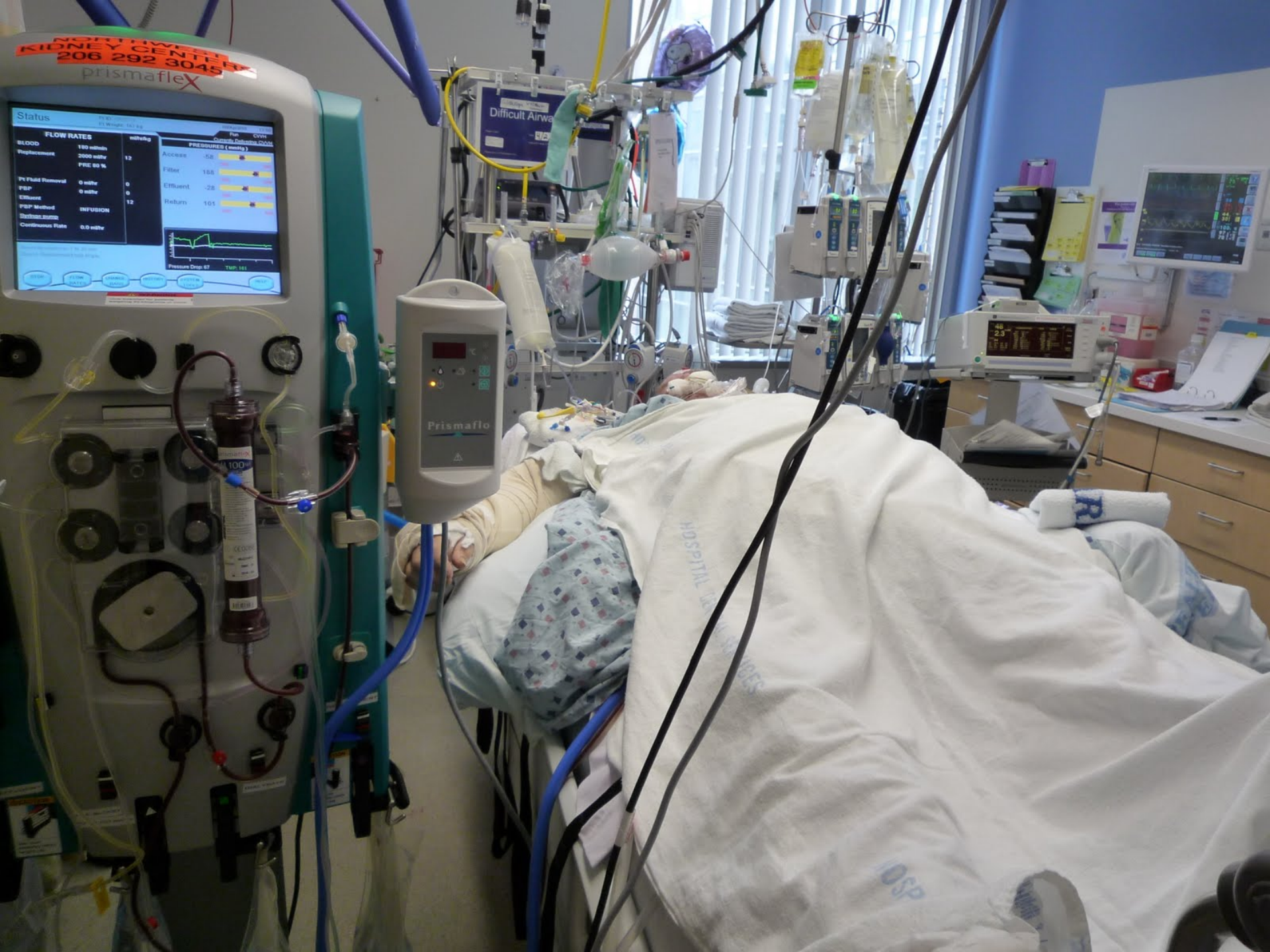

I in 4 hospital deaths are in ICU
Many of the rest we see at Rapid Response calls

W B Yeats

“Sex and death are the only things that can interest a serious mind.”

.....Also sport

Aging
Frailty
Loss of capacity
Hard decisions
Dying


NORTHWEST
KIDNEY CENTERS
206 292 3045
prismaflex
Status
FLOW RATES
ml/hr/kg
BLOOD
180 ml/min
Replacement
2000 ml/hr
12
PRE 80 %
Pt Fluid Removal
0 ml/hr
0
PBP
0 ml/hr
0
Effluent
12
PBP Method
INFUSION
Continuous Rate
0.0 ml/hr
PRESSURES (mmHg)
Access -58
Filter 188
Effluent -28
Return 101
Pressure Drop: 67
TMP: 161
Prismaflo


How did we get here?

Drivers of change

- Demographic shift
- Materialism
- Autonomy/rights
- Medical technology
- Denial (unawareness) of death
- Conspiracy

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S., Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H., Nancy L. Keating, M.D., M.P.H., and Deborah Schrag, M.D., M.P.H.

- 70 - 80% expected a cure that wasn't going to happen
- The most popular oncologists were the most unrealistic

May 2015, Vol 1, No. 2 >

< Previous Article Next Article >

Original Investigation | May 2015

Patient Perception of Physician Compassion After a More Optimistic vs a Less Optimistic Message

A Randomized Clinical Trial FREE

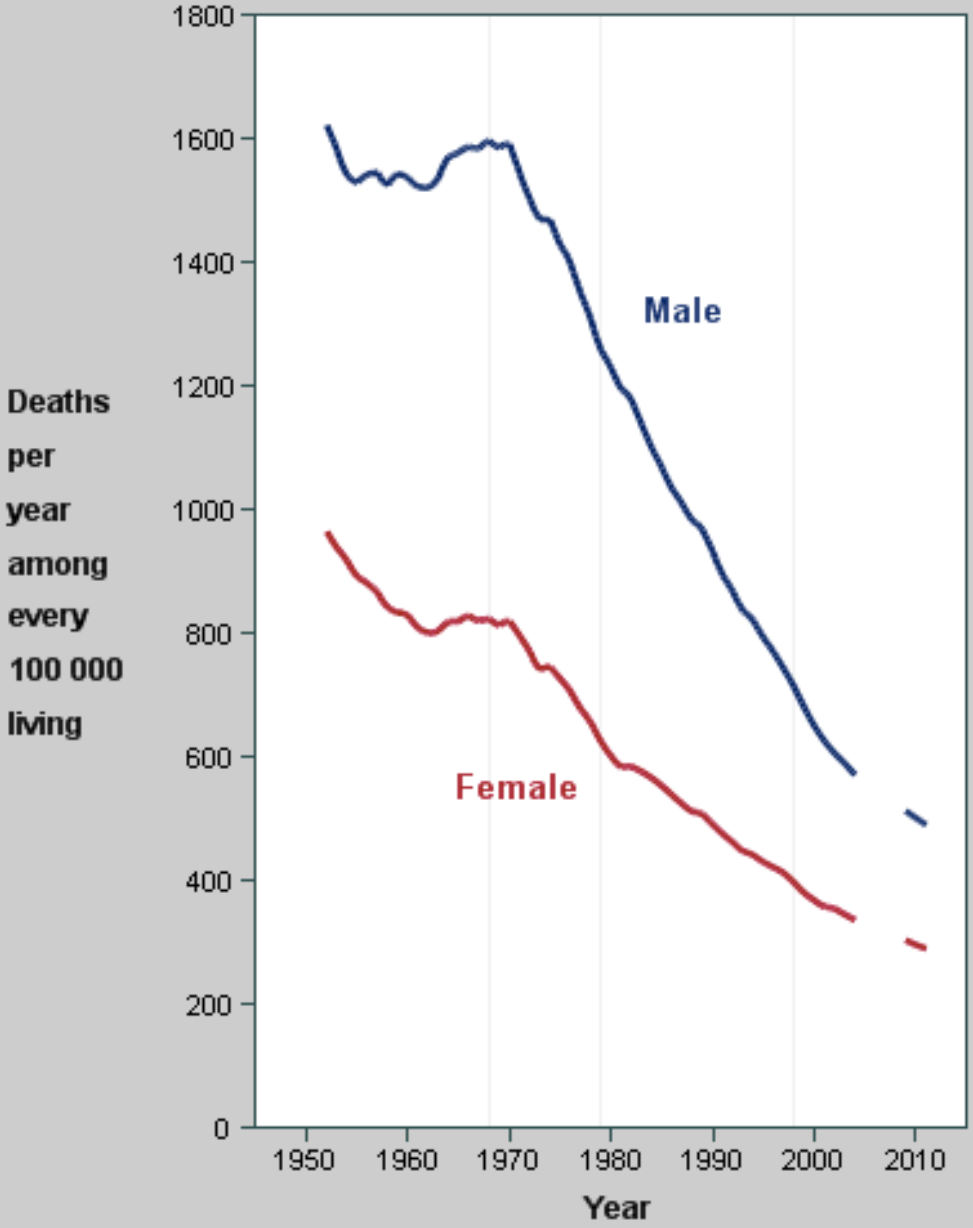
Kimberson Tanco, MD[1]; Wadih Rhondali, MD[1,2,3]; Pedro Perez-Cruz, MD[4]; Silvia Tanzi, MD[5]; Gary B. Chisholm, MS[6]; Walter Baile, MD[7]; Susan Frisbee-Hume, RN, MS, CCRC, OCN[1]; Janet Williams, MPH, CCRP[1]; Charles Masino, BA, MS[1]; Hilda Cantu, BS[1]; Amy Sisson, MS, MLS[8]; Joseph Arthur, MD[1]; Eduardo Bruera, MD[1]

Conclusions and Relevance Patients perceived a higher level of compassion and preferred physicians who provided a more optimistic message. More research is needed in structuring less optimistic message content to support health care professionals in delivering less optimistic news.

Drivers of change

- **Demographic shift**
- Materialism
- Autonomy/rights
- Medical technology
- Denial (unawareness) of death
- Conspiracy

Mortality trends for all causes of death: age 35-69 years, Australia



Male deaths from any cause at age 35-69 years in 2011:

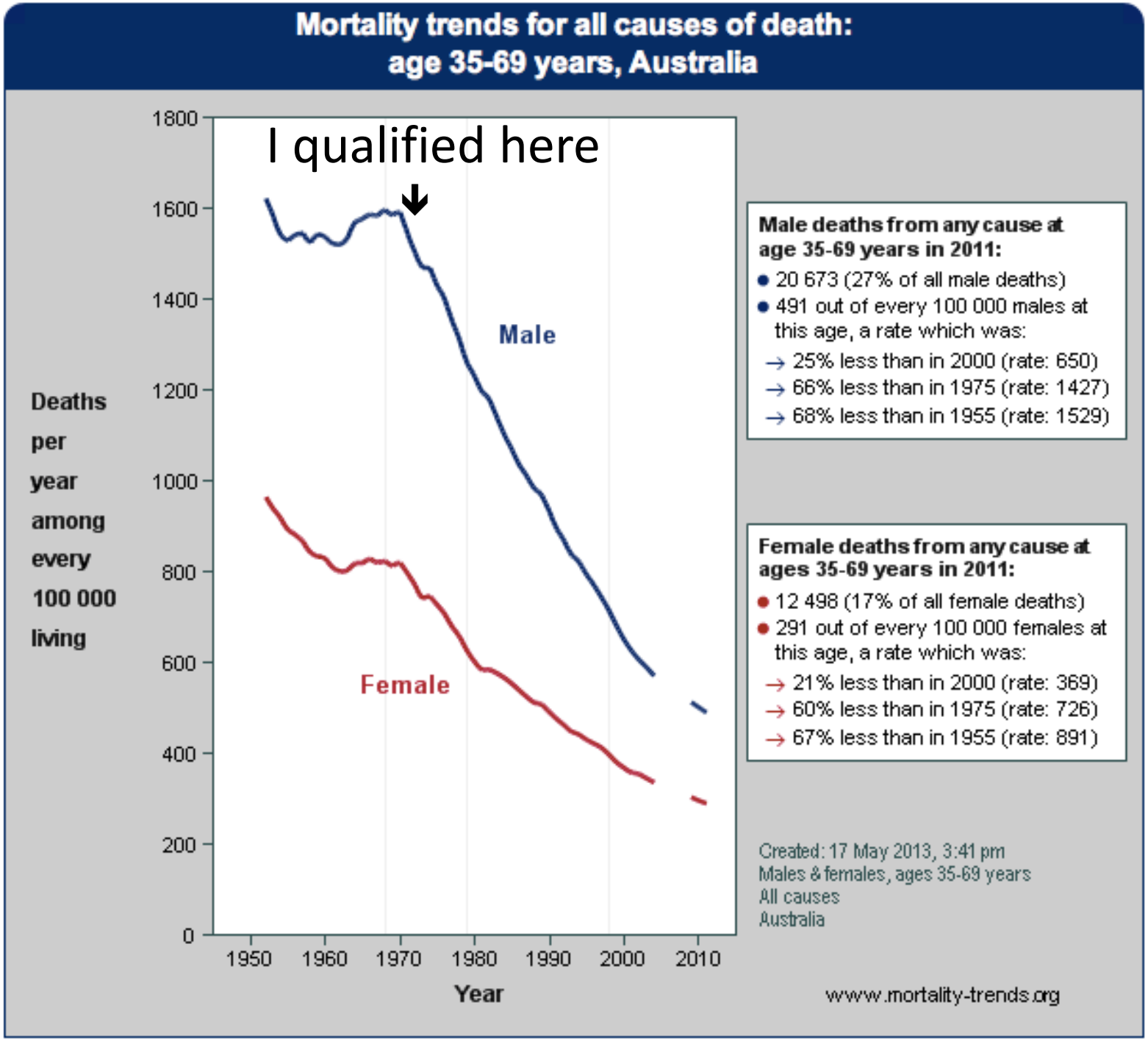
- 20 673 (27% of all male deaths)
- 491 out of every 100 000 males at this age, a rate which was:
  - → 25% less than in 2000 (rate: 650)
  - → 66% less than in 1975 (rate: 1427)
  - → 68% less than in 1955 (rate: 1529)

Female deaths from any cause at ages 35-69 years in 2011:

- 12 498 (17% of all female deaths)
- 291 out of every 100 000 females at this age, a rate which was:
  - → 21% less than in 2000 (rate: 369)
  - → 60% less than in 1975 (rate: 726)
  - → 67% less than in 1955 (rate: 891)

Created: 17 May 2013, 3:41 pm
Males & females, ages 35-69 years
All causes
Australia

www.mortality-trends.org


Mortality trends for all causes of death:
age 35-69 years, Australia
I qualified here
Male
Female
Deaths per year among every 100 000 living
1800
1600
1400
1200
1000
800
600
400
200
0
1950
1960
1970
1980
1990
2000
2010
Year
Male deaths from any cause at age 35-69 years in 2011:
20 673 (27% of all male deaths)
491 out of every 100 000 males at this age, a rate which was:
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→ 67% less than in 1955 (rate: 891)
Created: 17 May 2013, 3:41 pm
Males & females, ages 35-69 years
All causes
Australia
www.mortality-trends.org

Over 90% of Australians live to be old

Mostly due to a decision

Mostly made by others

In acute care

Not anticipated

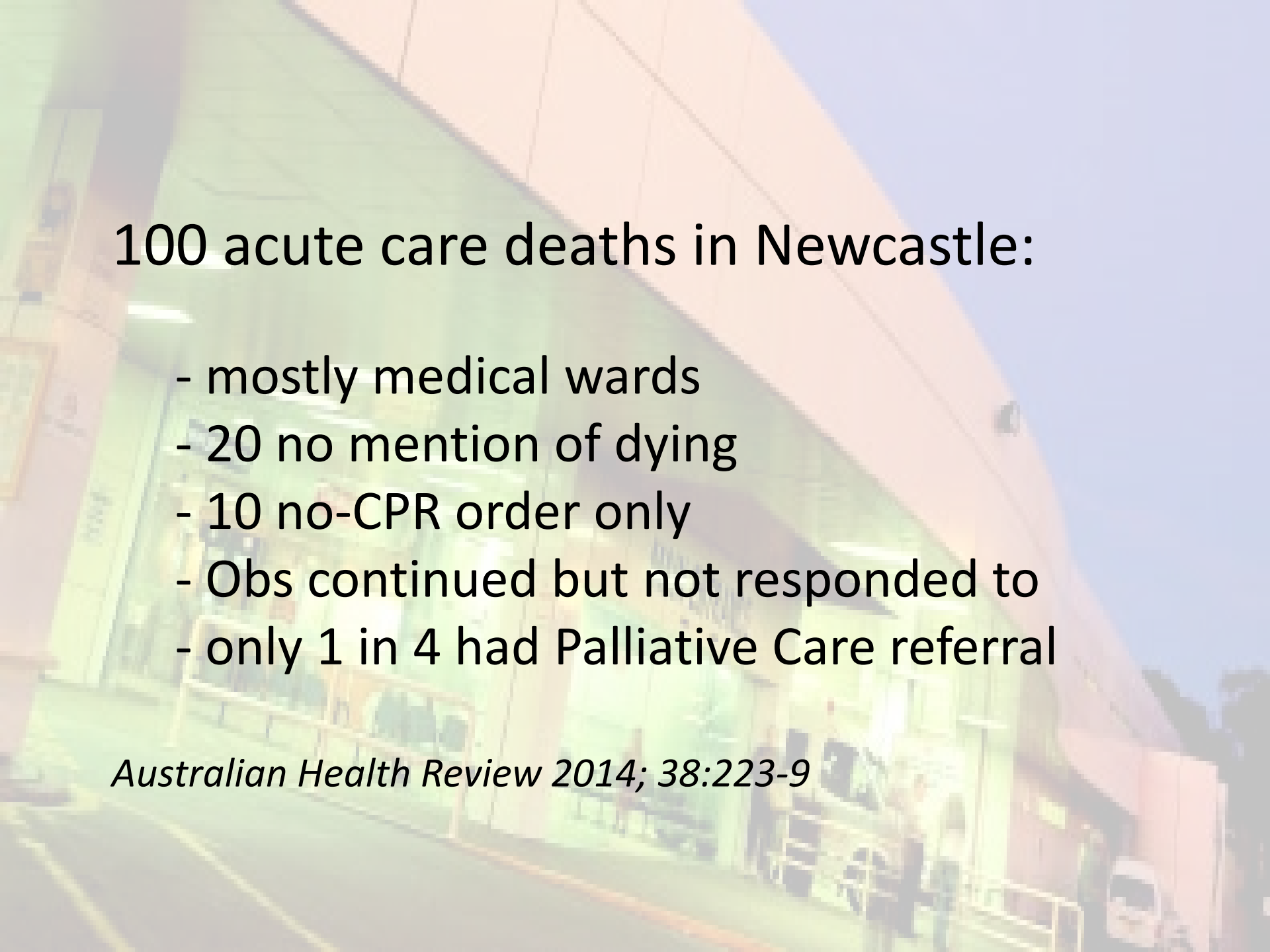
Poorly managed

No discussion of EOL until last 24hrs in 2 out of 3

Wishes known and followed in less than 1 in 4

Unresolved conflict in 1 in 3

Australian Health Review 2013;37:93-97



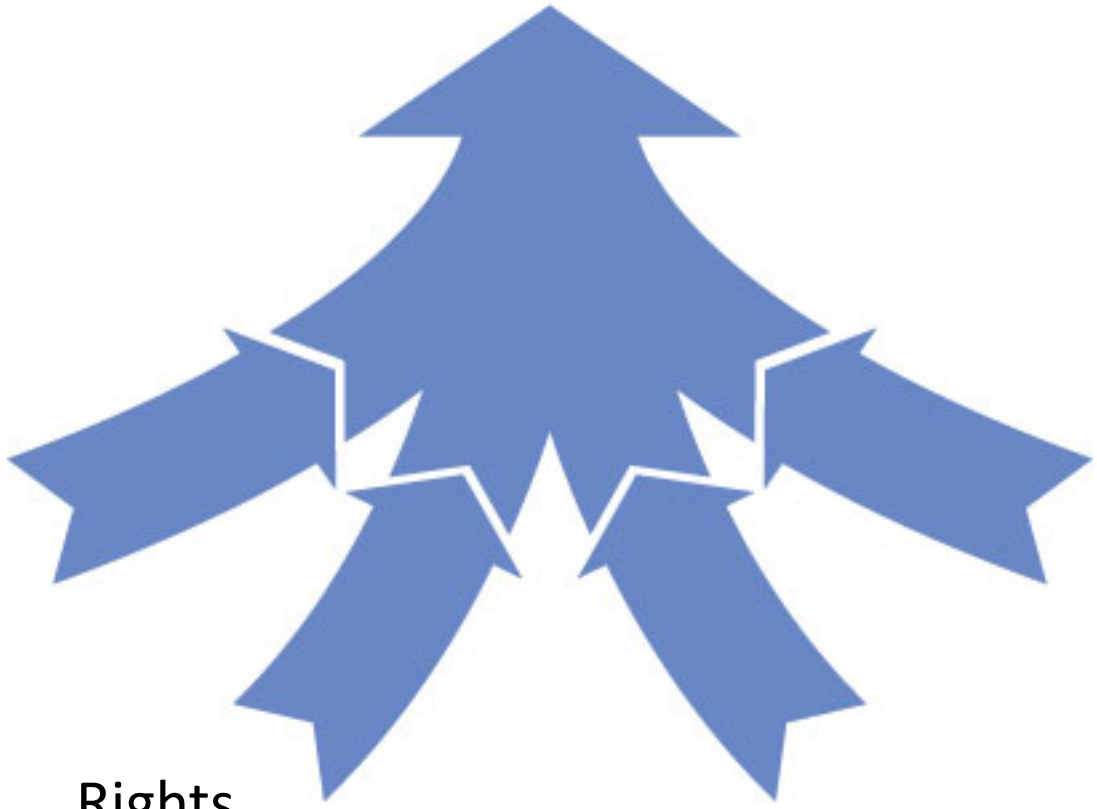
100 acute care deaths in Newcastle:

- mostly medical wards
- 20 no mention of dying
- 10 no-CPR order only
- Obs continued but not responded to
- only 1 in 4 had Palliative Care referral

Australian Health Review 2014; 38:223-9

Advance Care Planning

ACP



Bad research

EOL costs

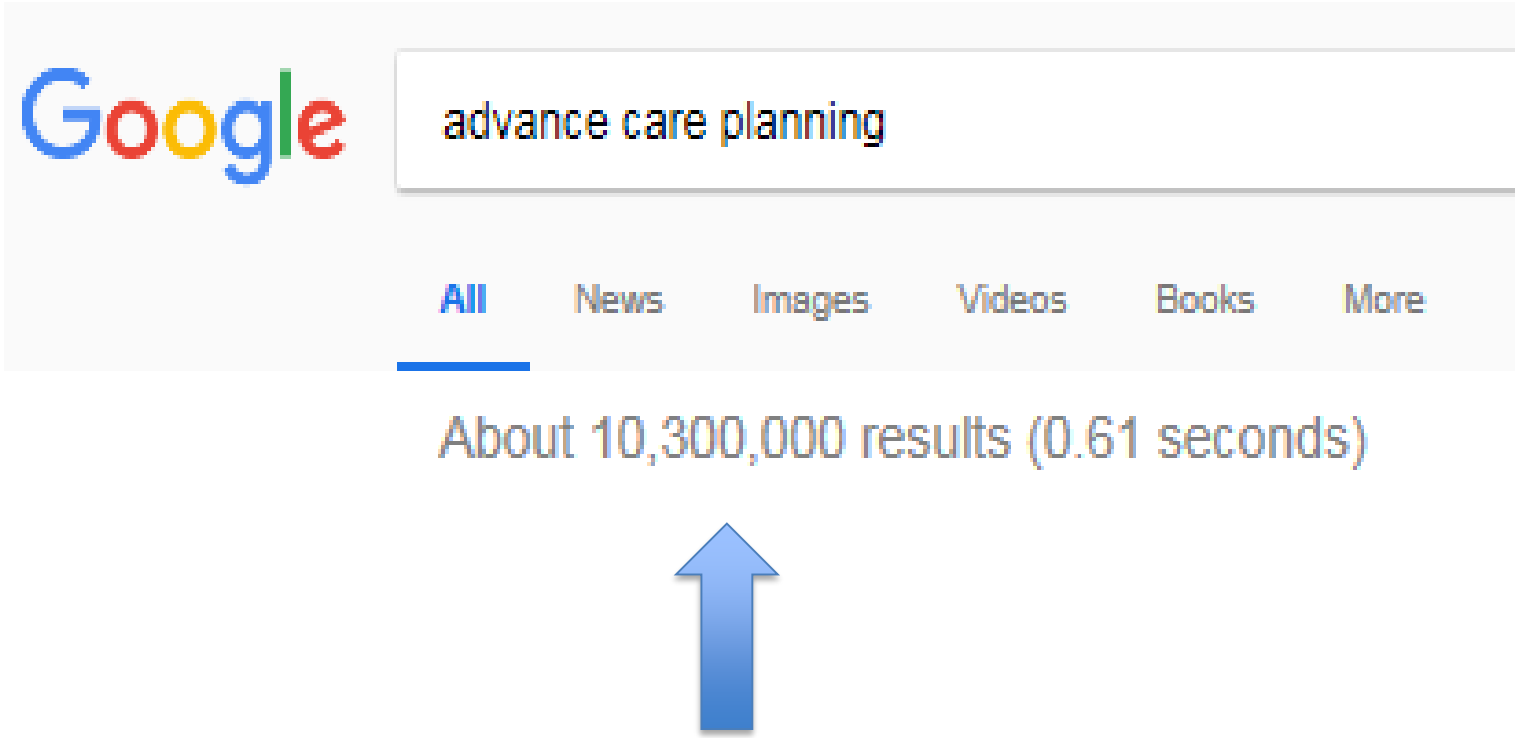
Rights

Ethical dilemma

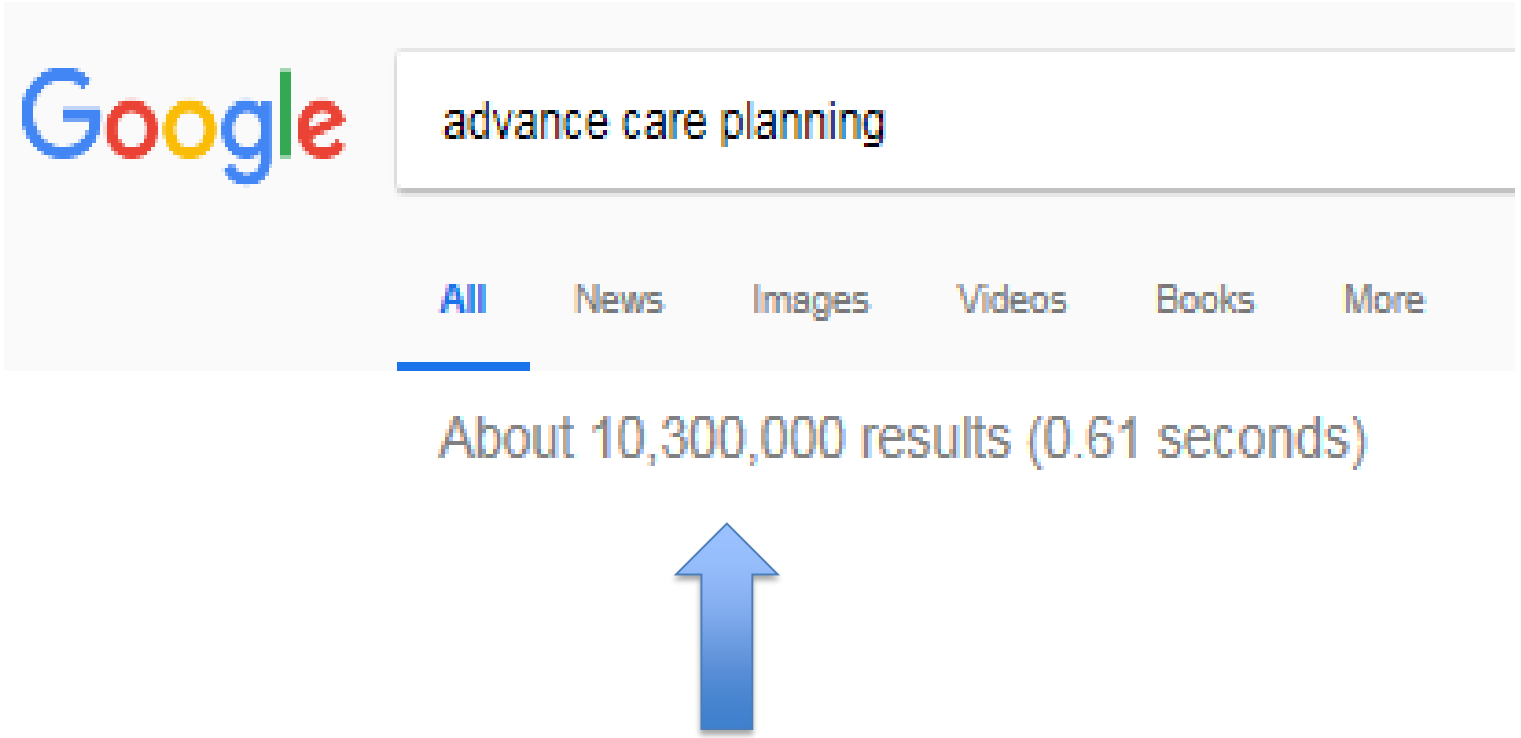
Research ethics promoted choice as the benchmark of morality

Advance Care Planning

We all understand it



We all understand it



This morning 15,400,000

We can all make choices

Even bad ones….

We are all rugged individuals who like to be in charge

No, no, no and no

Choice is not the issue. The misrepresentation of healthcare in bioethical discourse

Kari Milch Agledahl,[1] Reidun Førde,[3] Åge Wifstad[2]

The options patients do confront are somewhat arbitrarily constructed within the narrow framework of both what is deemed to be medically appropriate and how the healthcare system is organised practically.

Australians are weird (maerkelig?)

Australians are weird (maerkelig?)

Western
Educated
Industrialised
Rich
Democratic

Australians are weird (maerkelig?)

Western
Educated
Industrialised
Rich
Democratic

And still not very interested….

Advance Care Planning

What do we know?

Advance Care Planning

Advance Care Directive

Choosing who chooses

Complex interventions

- conversations
- support person
- shared decision making


ADVANCE DIRECTIVE
Prepared for

Historically linked with euthanasia

Legal transaction

Low uptake and availability

Poor response from doctors

Enough

The Failure of the Living Will

Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42.

Enough. The living will has failed, and it is time to say so.

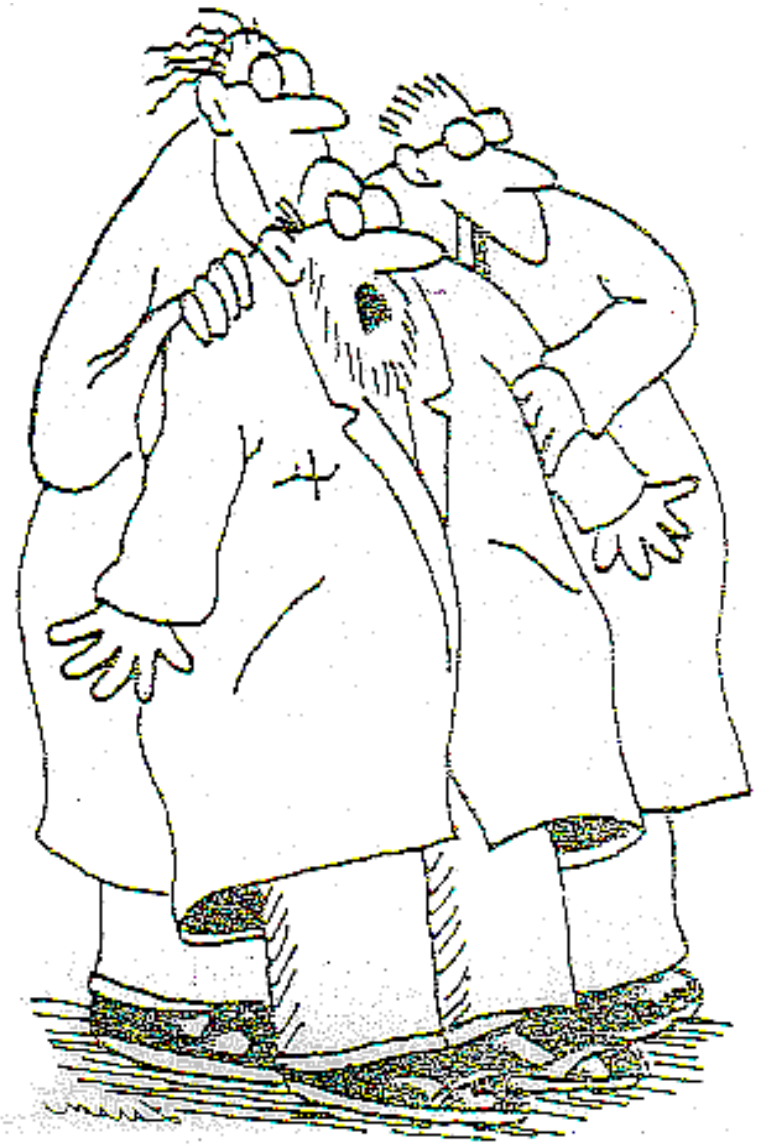
We should have known it would fail: A notable but neglected psychological literature always provided arresting reasons to expect the policy of living wills to misfire. Given their alluring potential, perhaps they were worth trying. But a crescendoing empirical literature and persistent clinical disappointments reveal that the rewards of the campaign to promote living wills do not justify its costs. Nor can any degree of tinkering ever make the living will an effective instrument of social policy.

“I’m trying to die correctly, but it’s very difficult, you know.”

Lawrence Durrell


Q: “How do dying people feel?”

A: Ambivalent

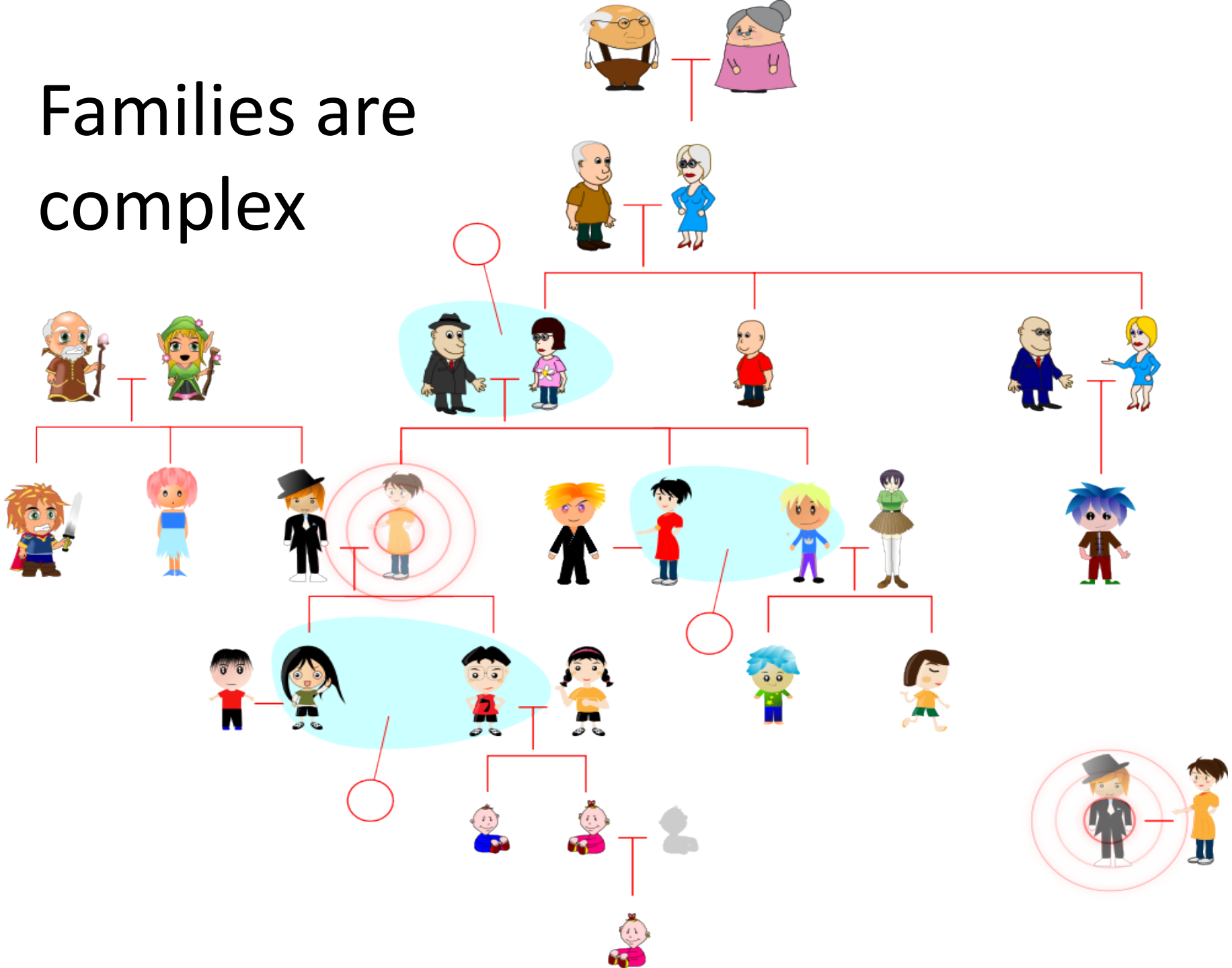


"There is always an easy solution to every human problem - neat, plausible, and wrong"

H L Mencken 1917

Choosing the chooser

Families are complex



My ICU study

- Can the “person to contact” listed on admission legally act as SDM?
- Is this “person to contact” acceptable to the patient’s family as SDM?
- What happens when the patient is asked?

Results

- No name captured in 10%.
- Not legally eligible to be SDM in 13%
- Remained in dispute throughout admission in 3%
- Family judged that this “person to contact” was the wrong person in 32%

Gender

- Person to contact on admission:
  - 30 wives vs 12 husbands
  - 15 daughters vs 9 sons
  - 7 mothers vs 5 fathers
  - “other” 7 female vs 3 male
- Overall
  - 66% of “persons to contact” were female.

“Wrong person”?

Wives: 9 of 30 overturned or resigned.

- 2 mentally ill
- 3 pushed aside by children
- 2 had just left the relationship
- 1 injured in same car crash
- 1 wouldn’t come

“Wrong person”?

- Daughters: 7 of 15 overturned/resigned.
  - 4 deferred to son
  - 1 never spoke to father (patient)
  - 2 wouldn’t come

Gender

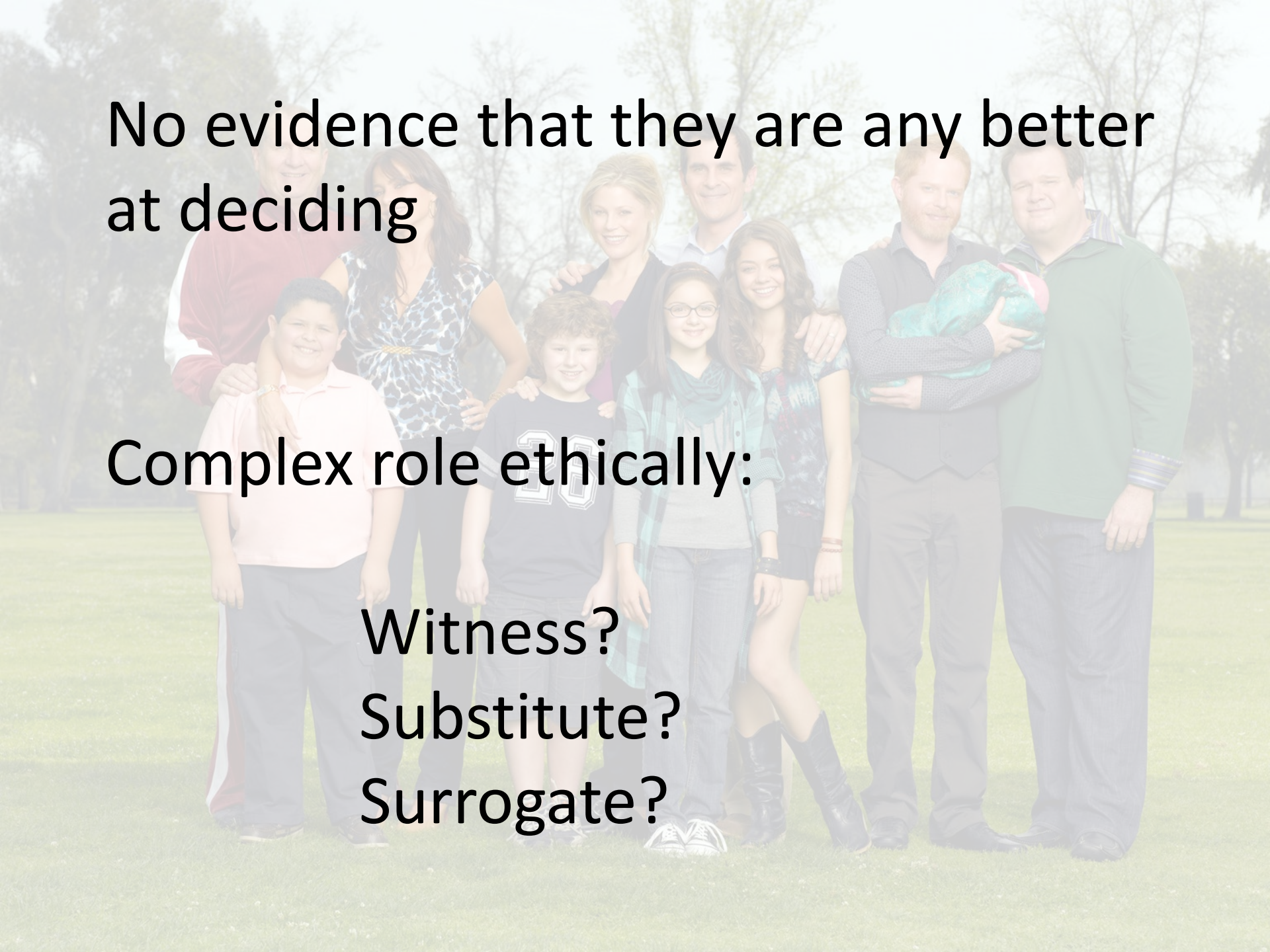
- Overall (after family discussions)
  - 21 females had been overturned (9 males)
  - Mostly replaced by males

What did the patients think?

- 10 patients regained capacity while in ICU
- 7 wanted a different person from the admission sheet *and* the family:
  - 1 wanted his wife (but she refused)
  - 1 had a partner we didn't know about
  - 1 preferred son over husband
  - 1 preferred father over girlfriend
  - 1 accepted his daughter back
  - 1 wanted a different friend
  - 1 preferred brother over mother

Summary of outcomes

- System problem
  - 10% not asked
  - 13% failed to find eligible decision maker
- High rate of intervention by the family
  - 32% came up with a different SDM during 48 hrs
- Women usually nominated, but many are replaced or fail to carry out role.
- Patient usually has a different (and unexpected) preference.



No evidence that they are any better at deciding

Complex role ethically:

Witness?
Substitute?
Surrogate?

The Facilitated Values History

Helping Surrogates Make Authentic Decisions for Incapacitated Patients with Advanced Illness

Leslie P. Scheunemann[1,2,3], Robert M. Arnold[4,5], and Douglas B. White[6,7]

AUTONOMOUS DECISIONS OR AUTHENTIC DECISIONS?

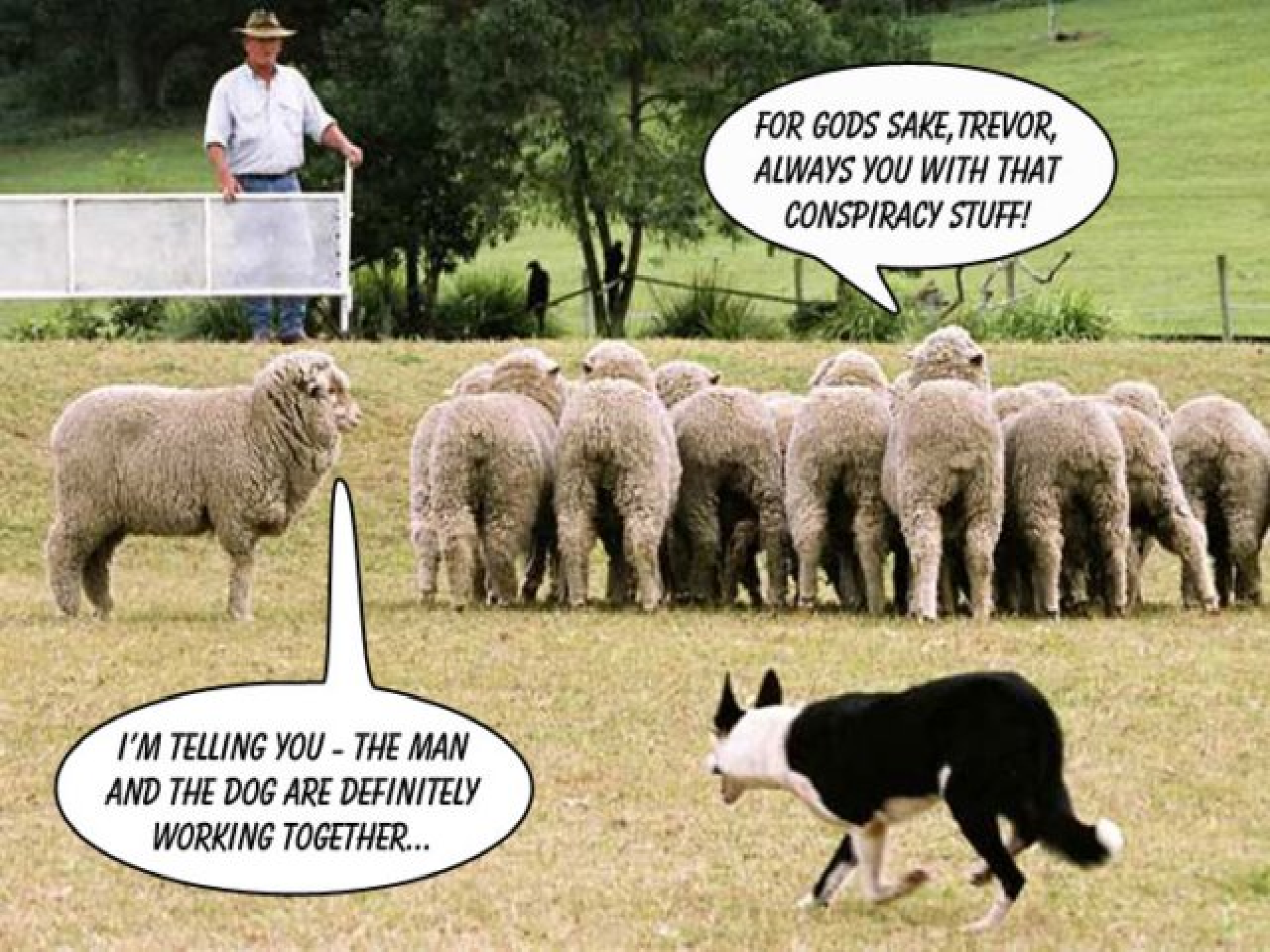
A common misperception among clinicians is that respect for autonomy is the ethical principle that drives most decisions for incapacitated patients (15). However, a decision cannot be autonomous unless the patient actually made a specific choice in advance about the medical situation at hand. When the incapacitated patient has not previously communicated a relevant, applicable choice, as is generally the case in ICUs, clinicians cannot be guided primarily by respect for autonomy. Instead,

Imagine you are in a restaurant….


X Desktop Wallpapers.Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com


XDesktopWallpapers.com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com
X Desktop Wallpapers Dot Com

Let’s vote…


FOR GODS SAKE, TREVOR, ALWAYS YOU WITH THAT CONSPIRACY STUFF!
I'M TELLING YOU - THE MAN AND THE DOG ARE DEFINITELY WORKING TOGETHER...

Advance Care Planning

Advance Care Directive

Choosing who chooses

Complex interventions

- conversations
- support person
- shared decision making

Review Article

PALLIATIVE MEDICINE

The effects of advance care planning on end-of-life care: A systematic review

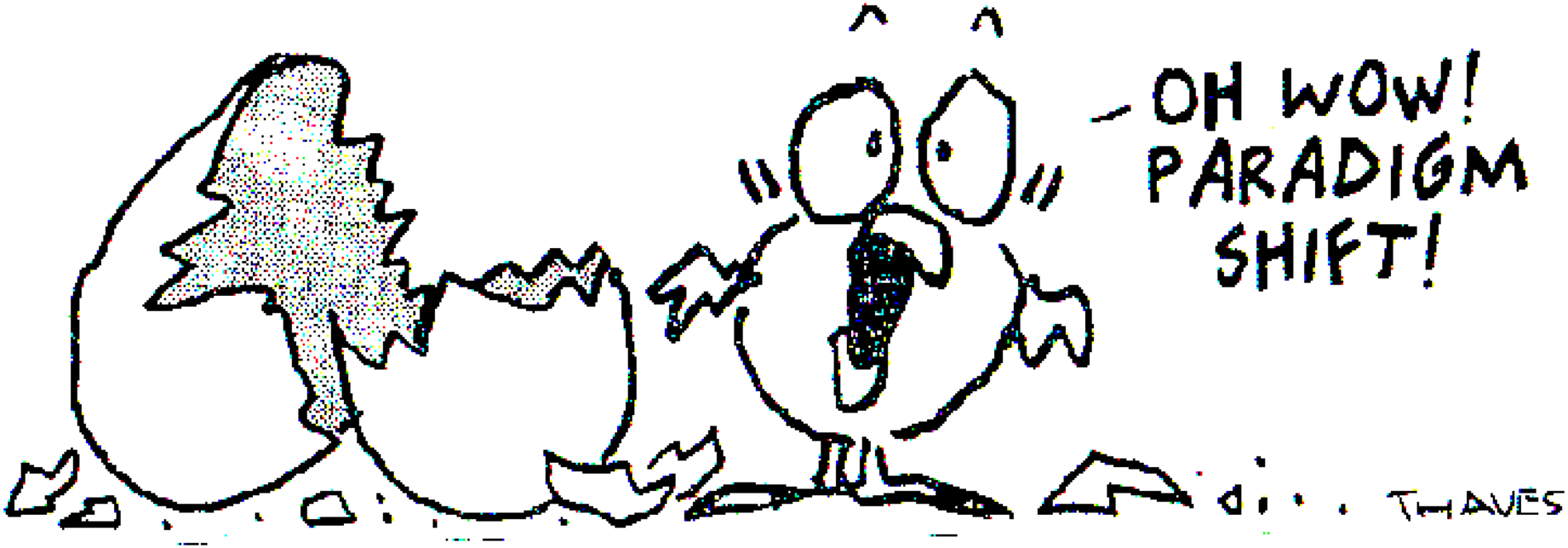
Palliative Medicine
2014, Vol. 28(8) 1000–1025

DOI: 10.1177/0269216314526272
pmj.sagepub.com
SAGE

Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide

"…complex interventions more effective than written instructions"

(people/literature/iterative/step-wise approaches)


OH WOW!
PARADIGM
SHIFT!
THAVES

Trained all staff to have ACP conversations

Highly positive result

Not sustained when funding stopped

MY NetCare

A HUNTER ALLIANCE INITIATIVE

Health Touchpoints Graph:
Patients with a Serious Advanced Illness in the last year of life

General Practitioner		14
Specialist		8
Emergency		3
Hospital Admission		3
Ambulance		4
Community Nurse		8
Pharmacist		21
Social Worker		2
Physiotherapist		4
Pathology Services		8
Podiatry		5
Homecare		25

MY NetCare
A HUNTER ALLIANCE INITIATIVE

Patients identified as being in the **last year of life**

90% had no computer

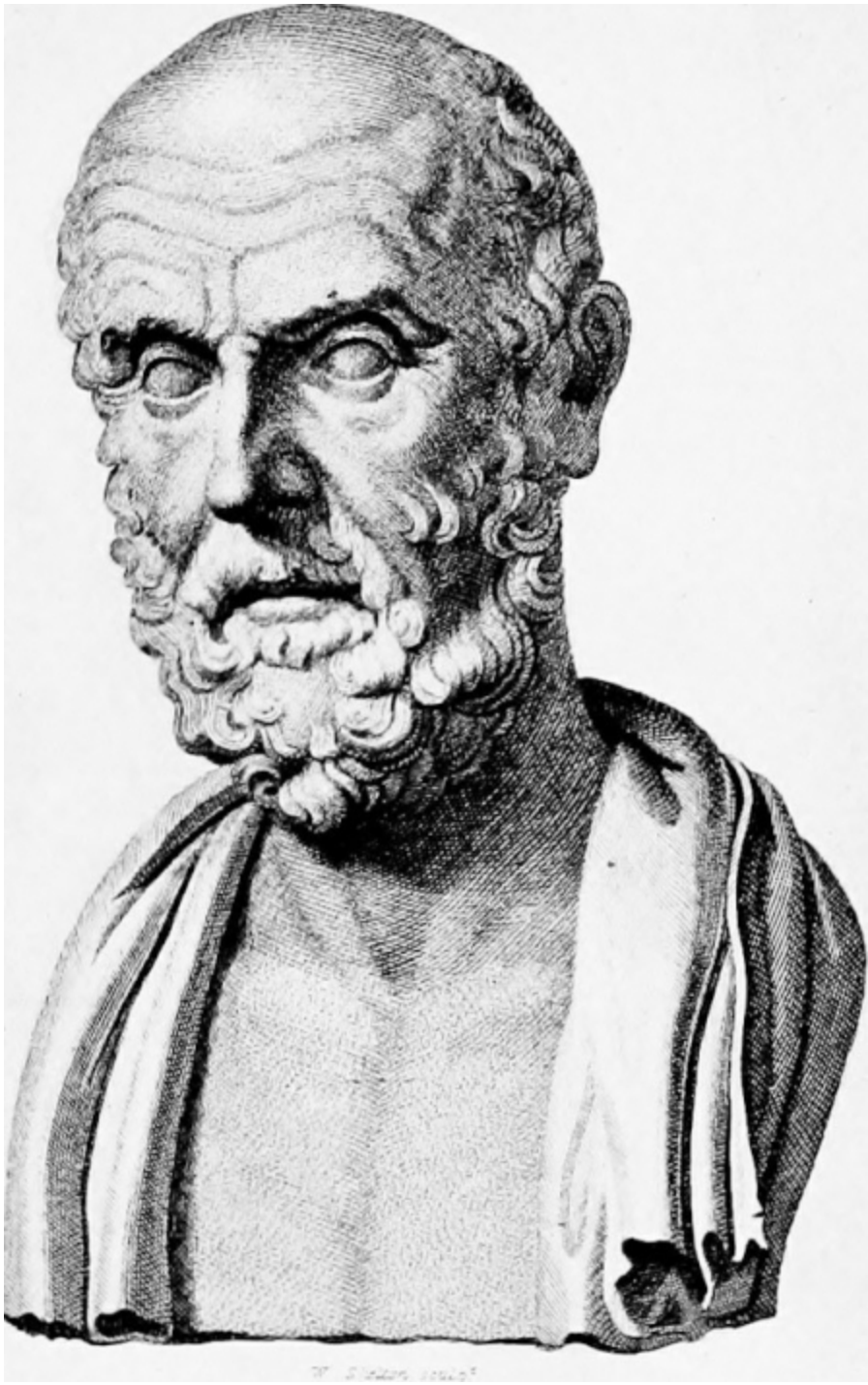
50% already dependent on a carer

Most did not know about ACP and had no plan

Most wanted to make a plan with the MyNetCare recruiter


Shared decision
making

"…patients must place themselves fully in physicians' hands and obey commands"



SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO)

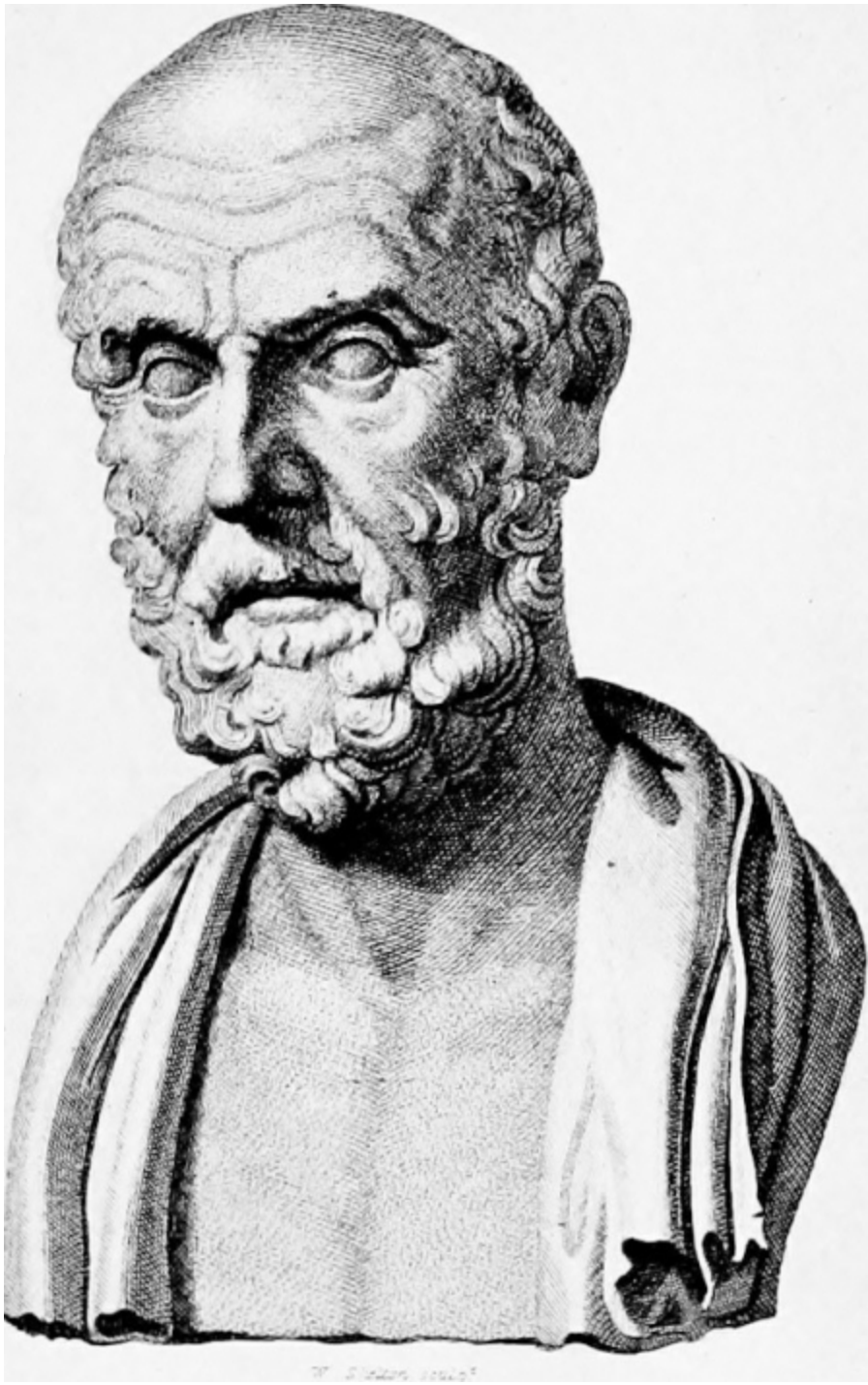
CATHY CHARLES,[1,2,3]* AMIRAM GAFNI[1,2,3] and TIM WHELAN[3,4,5]

[1]Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario,

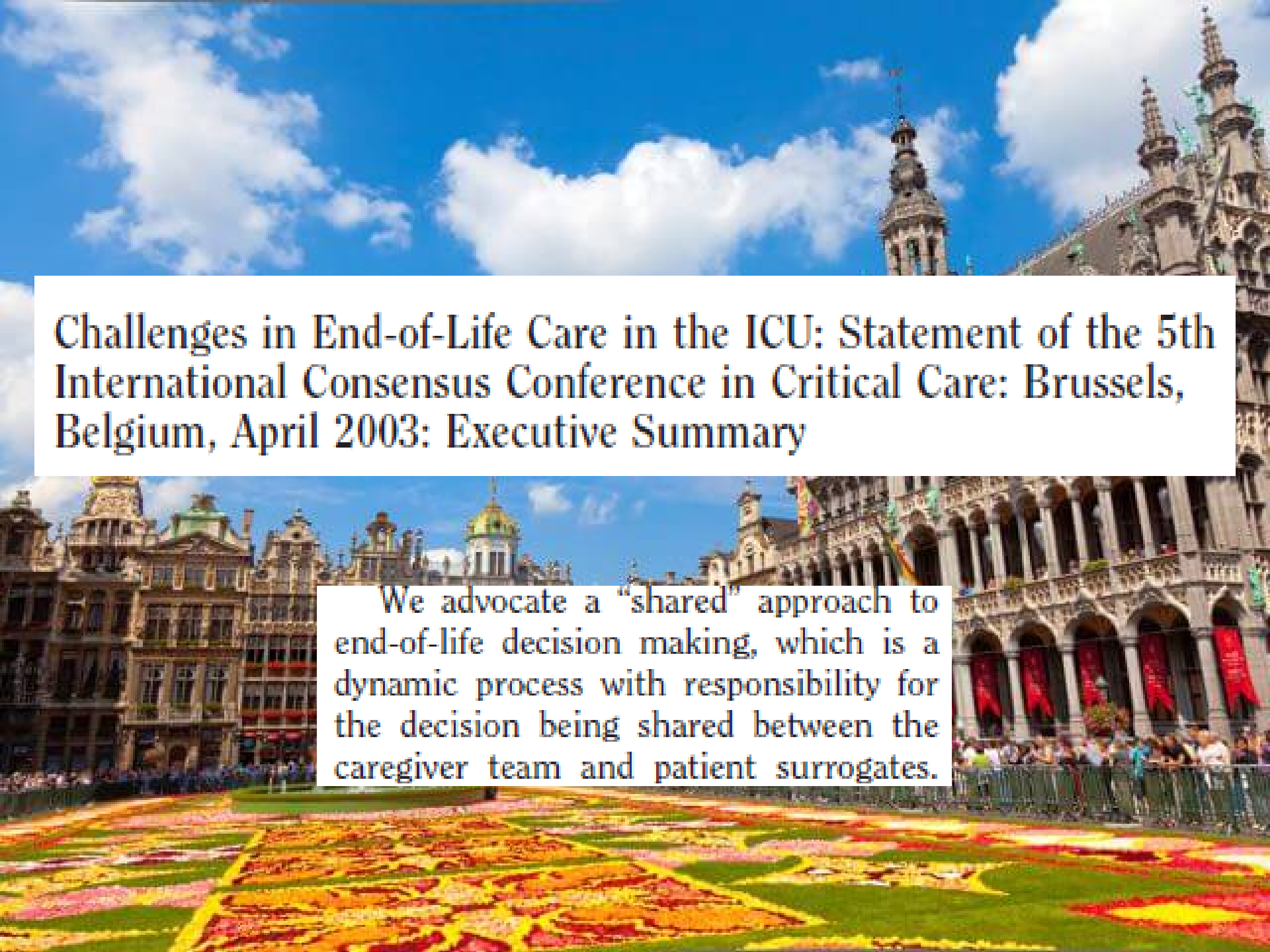
Shared decisions (Charles 1997)

- "..for shared decisions to occur, there needs to be a two-way exchange not only of information but of ***treatment preferences***."
- Both/all parties have to be willing
- Information sharing
- Agree to be bound by the decision

"…patients must place themselves fully in physicians' hands and obey commands"



Challenges in End-of-Life Care in the ICU: Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: Executive Summary



Challenges in End-of-Life Care in the ICU: Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: Executive Summary

We advocate a "shared" approach to end-of-life decision making, which is a dynamic process with responsibility for the decision being shared between the caregiver team and patient surrogates.

PERSPECTIVE

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A.

Do you want to make your own decisions?

no_____maybe_____yes

Ende 1989

Do you want to make your own decisions?

no_____maybe_____yes

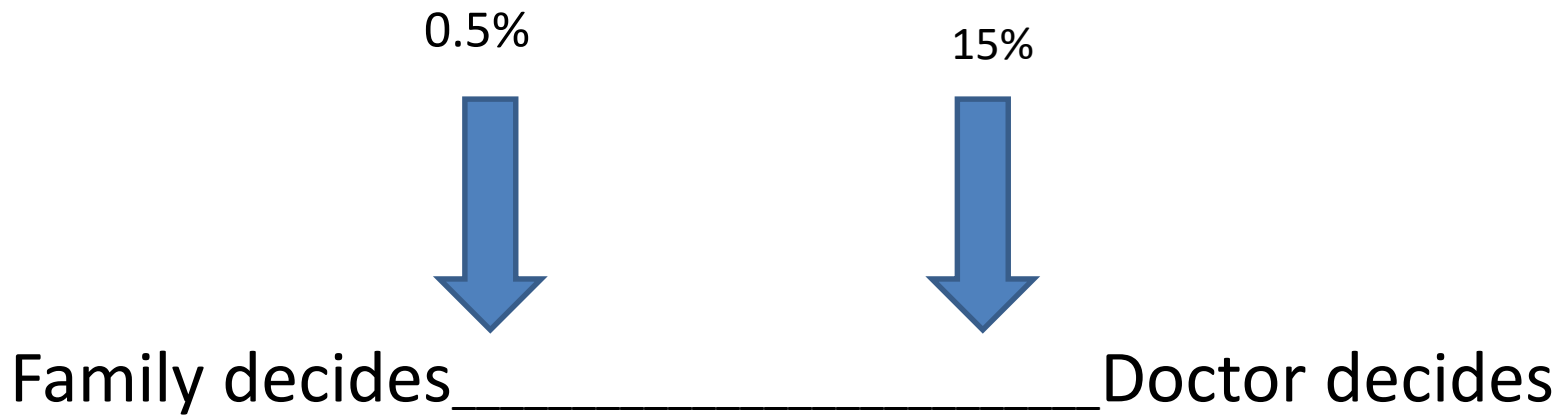
Ende 1989

Who should decide what to do with your Mum?

Family decides_____Doctor decides

Heyland 2003

Who should decide what to do with your Mum?



Heyland 2003

REALITY

Worst game ever.

Table 2 Components of Shared Decision Making in Included Studies

Components of SDM[10–12]	Study						
	Briggs and Others[20] (2004)	Cox and Others[22] (2012)	Jacobsen and Others[21] (2011)	Noguera and Others[24] (2014)	Song and Others[25] (2013)	White and Others[12] (2007)	Witkamp and Others[23] (2014)
Patient/caregiver involvement in the decision making process	X	X	X	X	X	X	X
Providing information about disease state and prognosis		X	X		X	X	
Assessing understanding of information	X				X	X	
Providing information about treatment choices	X	X	X		X	X	
Providing information about risks and benefits of choices	X	X	X		X	X	
Eliciting values and goals		X	X		X	X	
Eliciting treatment preferences		X			X	X	
Eliciting decision making role preference (autonomous, shared, passive, etc.)		X				X	
Providing clinician recommendations in the context of the decision taking into consideration patients' informed values and goals			X				

Hajizadeh 2016

1. Nature of decision
2. Treatment alternatives
3. Pros and cons
4. Uncertainty
5. Understanding
6. Patient's values
7. Family's role
8. Need for input from others
9. Context of decision
10. Family's opinion about the decision

< 2%

Beaussant et al. BMC Palliative Care (2015) 14:61
DOI 10.1186/s12904-015-0057-4

BMC Palliative Care

RESEARCH ARTICLE Open Access

Is shared decision-making vanishing at the end-of-life? A descriptive and qualitative study of advanced cancer patients' involvement in specific therapies decision-making

Is Shared Decision Making for End-of-Life Decisions Associated With Better Outcomes as Compared to Other Forms of Decision Making? A Systematic Literature Review

Negin Hajizadeh, MD, MPH, Lauren Uhler, MPH, Saori Wendy Herman, MLIS, AHIP, Janice Lester, MLS

DEBATE Open Access

Implementing shared decision-making: consider all the consequences

Glyn Elwyn[1*], Dominick L. Frosch[2,3] and Sarah Kobrin[4]


OVERWHELMING EVIDENCE

Not just a paradigm shift……

…..more like a revolution

Philosophically different

John Stuart Mill…

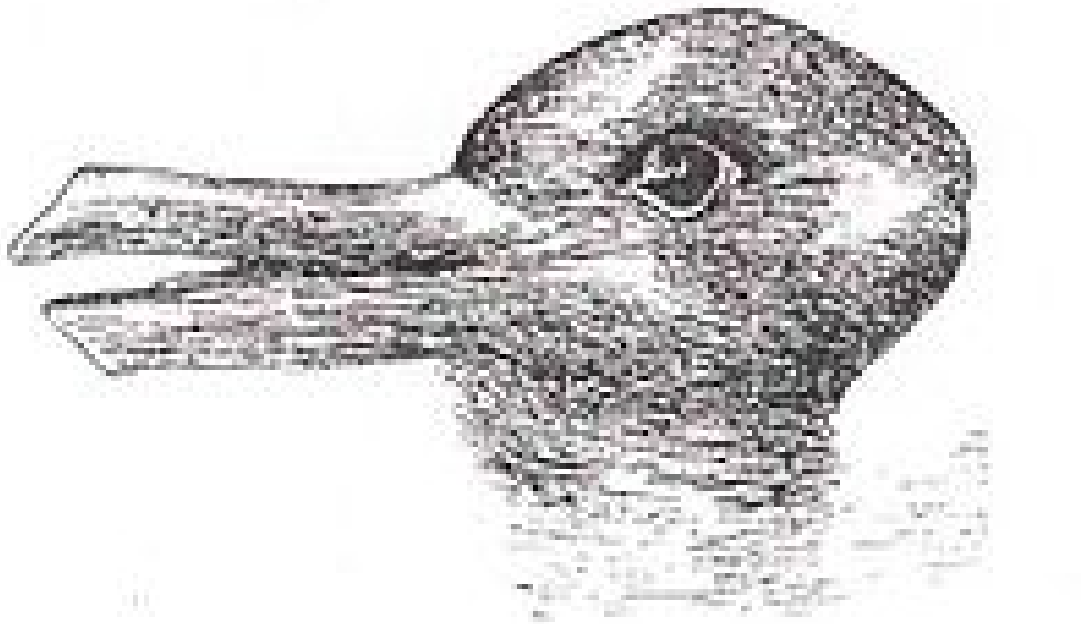
“The sole end for which mankind are warranted in interfering with the liberty of action of any of their number is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant”.

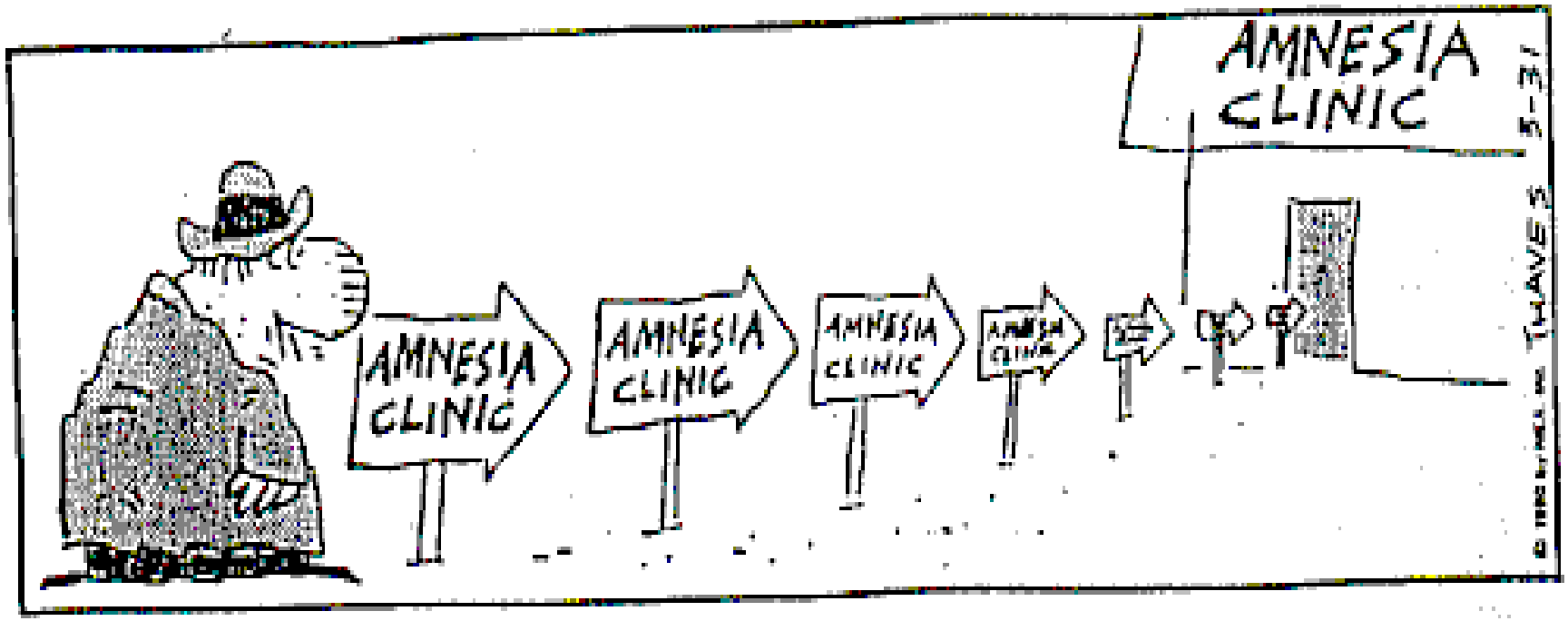
Feminist philosophy and “relational autonomy”

Annette Baier

“If we ask ourselves what actually enables people to be autonomous, the answer is not isolation but relationships – with parents, teachers, friends, loved ones”

People need help to be independent




AMNESIA CLINIC
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5-31
THAVES

ACP - Practical conclusions

- Take the focus away from dying
- It’s a supported conversation, not a legal contract
- It’s not owned by the Palliative Care Service
- Keep it separate from euthanasia
- Online?

Theoretical conclusions

- ACP has made a lot of mistakes, and was based on the wrong philosophy.
- Shared decision making is nothing less than a revolution in medicine
- Embrace ambivalence and bad choices
- Maybe all we are trying to do is build trust

“The great thing about failure is that it requires no preparation”


Thank you


“How we die remains in the memories of those who live on”

Euthanasia

Plan for lack of capacity