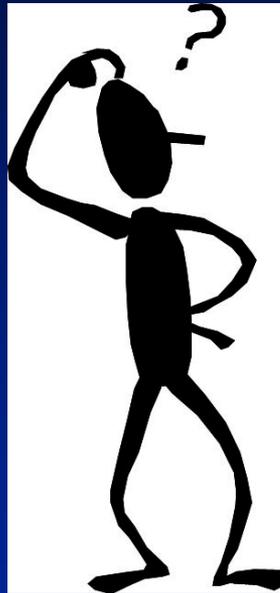


End of Life Matters in ICU.

Decisions in (*and outside of*) Intensive Care



***Mary White MB BCh BAO FFARCSI,
Intensive Care Unit,
Royal Adelaide Hospital.***

YES WE CAN



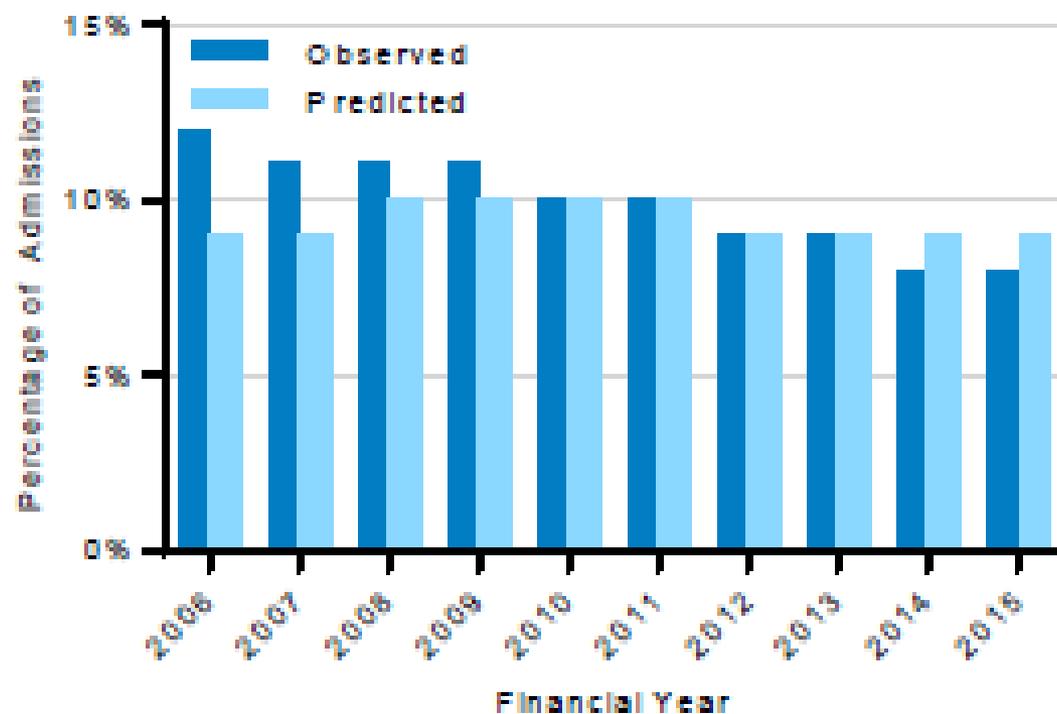
Primum non nocere.

Death

- **Absolute certainty (like taxes!).**
- **Part of a process.**
- **Not a defeat or a failure.**

Media vita in morte sumus; in the midst of life we are in death

Figure 30: Observed and predicted hospital mortality – 10yr trend



Source: APD, predicted mortality derived from ANZROD calibrated to 2011/2012



ANZICS

Australian and New Zealand Intensive Care Society (ANZICS)

ACN 057 619 986

**ANZICS Statement on
Care and Decision-Making at the End of Life
for the Critically Ill**

Edition 1.0

2014

Principles of intensive care.

- Intensive care good if reversible illness
- Ethical principles---beneficence and non-maleficence
- Benefits of treatment vs. burdens---probability rather than certainty
- No obligation to initiate ineffective therapy
- Competent adult / Patient's views or surrogate
- Alternative care plan
- Consensus--- medical and family
- Withholding equivalent to withdrawal

Is it all about survival?



Functional Disability 5 Years after Acute Respiratory Distress Syndrome

Margaret S. Herridge, M.D., M.P.H., Catherine M. Tansey, M.Sc., Andrea Matté, B.Sc., George Tomlinson, Ph.D., Natalia Diaz-Granados, M.Sc., Andrew Cooper, M.D., Cameron B. Guest, M.D., C. David Mazer, M.D., Sangeeta Mehta, M.D., Thomas E. Stewart, M.D., Paul Kudlow, B.Sc., Deborah Cook, M.D.

Long-Term Quality of Life Among Survivors of Severe Sepsis: Analyses of Two International Trials*

Sachin Yende, MD, MS^{1,2}; Shamly Austin, PhD, MHA^{1,2}; Andrew Rhodes, MD³; Simon Finfer, MD, FCICM⁴; Steven Opal, MD⁵; Taylor Thompson, MD⁷; Fernando A. Bozza, MD, PhD^{1,8}; Steven P. LaRosa, MD⁹; V. Marco Ranieri, MD¹⁰; Derek C. Angus, MD, MPH¹

Long-term Cognitive Impairment and Functional Disability Among Survivors of Severe Sepsis

Theodore J. Iwashyna, MD, PhD
E. Wesley Ely, MD, MPH
Dylan M. Smith, PhD
Kenneth M. Langa, MD, PhD

COGNITIVE IMPAIRMENT AND physical disability are major health burdens and drivers of health care costs. The onset of disability is associated with worsened mortality¹ and substantial increases in medical costs over subsequent years,² including a disproportionate strain on Medicaid and Medicare. Both cognitive and physical disability impose yet further burdens on families and informal caregivers.³ Irreversible cognitive and physical impairment following acute illnesses are particularly feared outcomes and weigh heavily on patient decision making.⁴

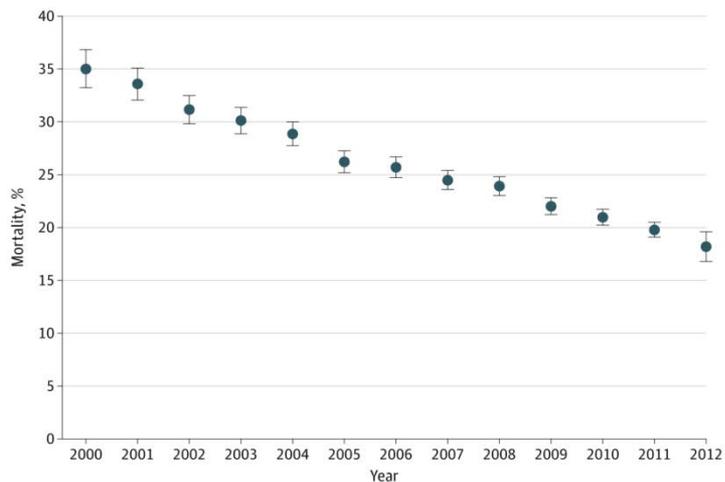
Context Cognitive impairment and functional disability are major determinants of caregiving needs and societal health care costs. Although the incidence of severe sepsis is high and increasing, the magnitude of patients' long-term cognitive and functional limitations after sepsis is unknown.

Objective To determine the change in cognitive impairment and physical functioning among patients who survive severe sepsis, controlling for their pre-sepsis functioning.

Design, Setting, and Patients A prospective cohort involving 1194 patients with 1520 hospitalizations for severe sepsis drawn from the Health and Retirement Study, a nationally representative survey of US residents (1998-2006). A total of 9223 respondents had a baseline cognitive and functional assessment and had linked Medicare claims; 516 survived severe sepsis and 4517 survived a nonsepsis hospitalization to at least 1 follow-up survey and are included in the analysis.

Main Outcome Measures Personal interviews were conducted with respondents or proxies using validated surveys to assess the presence of cognitive impairment and to determine the number of activities of daily living (ADLs) and Instrumental ADLs (IADLs) for which patients needed assistance.

Results Survivors' mean age at hospitalization was 76.9 years. The prevalence of moderate to severe cognitive impairment increased 10.6 percentage points among patients who survived severe sepsis, an odds ratio (OR) of 3.34 (95% confidence interval [CI], 1.53-7.25) in multivariable regression. Likewise, a high rate of new functional limitations was seen following sepsis: in those with no limits before sepsis, a mean 1.57 new limitations (95% CI, 0.99-2.15); and for those with mild to moderate limitations before sep-



No. of patients 2708 3783 4668 5221 6375 6987 7627 8529 8797 10277 11367 12213 12512

ARDS: PTSD
Severe exercise limitation

Sepsis: 30% dead at 6 months
30% dependent at 6 months
New cognitive impairment

From: Mortality Related to Severe Sepsis and Septic Shock Among Critically Ill Patients in Australia and New Zealand, 2000-2012

Functional Disability 5 Years after Acute Respiratory Distress Syndrome

Margaret S. Herridge, M.D., M.P.H., Catherine M. Tansey, M.Sc., Andrea Matté, B.Sc., George Tomlinson, Ph.D., Natalia Diaz-Granados, M.Sc., Andrew Cooper, M.D., Cameron B. Guest, M.D., C. David Mazer, M.D., Sangeeta Mehta, M.D., Thomas E. Stewart, M.D., Paul Kudlow, B.Sc., Deborah Cook, M.D., Arthur S. Slutsky, M.D., and Angela M. Cheung, M.D., Ph.D.,
for the Canadian Critical Care Trials Group

ABSTRACT

BACKGROUND

There have been few detailed, in-person interviews and examinations to obtain follow-up data on 5-year outcomes among survivors of the acute respiratory distress syndrome (ARDS).

METHODS

We evaluated 109 survivors of ARDS at 3, 6, and 12 months and at 2, 3, 4, and 5 years after discharge from the intensive care unit. At each visit, patients were interviewed and examined; underwent pulmonary-function tests, the 6-minute walk test, resting and exercise oximetry, chest imaging, and a quality-of-life evaluation; and reported their use of health care services.

RESULTS

At 5 years, the median 6-minute walk distance was 436 m (76% of predicted distance) and the Physical Component Score on the Medical Outcomes Study 36-Item Short-Form Health Survey was 41 (mean norm score matched for age and sex, 50). With respect to this score, younger patients had a greater rate of recovery than older patients, but neither group returned to normal predicted levels of physical function at 5 years. Pulmonary function was normal to near-normal. A constellation of other physical and psychological problems developed or persisted in patients and family caregivers for up to 5 years. Patients with more coexisting illnesses incurred greater 5-year costs.

CONCLUSIONS

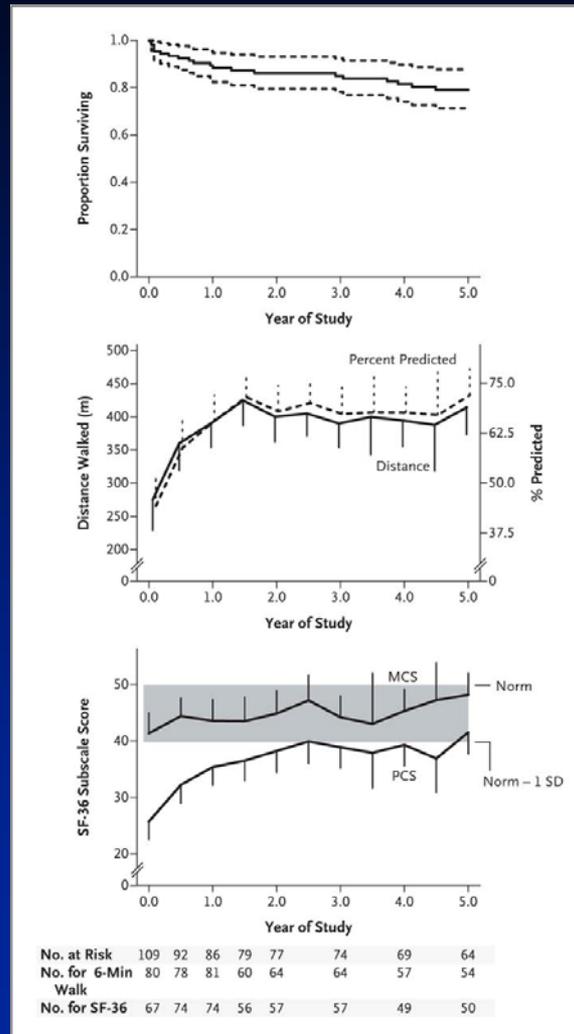
Exercise limitation, physical and psychological sequelae, decreased physical quality of life, and increased costs and use of health care services are important legacies of severe lung injury.

From the Department of Medicine, University Health Network (M.S.H., C.M.T., A.M., G.T., P.K., A.M.C.); the Interdepartmental Division of Critical Care (M.S.H., A.C., C.B.G., C.D.M., S.M., T.E.S., A.S.S.); the Department of Public Health Sciences (N.D.-G., A.M.C.); the Departments of Critical Care Medicine and Anesthesia, Sunnybrook Health Sciences Centre (A.C., C.B.G.); the Departments of Anesthesia (C.D.M.) and Medicine and Critical Care Medicine (A.S.S.) and the Keenan Research Center at the Li Ka Shing Knowledge Institute (C.D.M., A.S.S.), St. Michael's Hospital; the Dalla Lana School of Public Health (G.T., N.D.-G., A.M.C.) and the Departments of Medicine (S.M., T.E.S.) and Anesthesia (T.E.S.), Mount Sinai Hospital — all at the University of Toronto, Toronto; and the Departments of Medicine and Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada (D.C.). Address reprint requests to Dr. Herridge at Toronto General Hospital, NCSB 11C-1180, 585 University Ave., Toronto, ON M5G 2N2, Canada, or at margaret.herridge@uhn.on.ca.

N Engl J Med 2011;364:1293-304.

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Survival Rates, 6-Minute Walk Distance, and Quality of Life for 5 Years after Discharge from the Intensive Care Unit.



Herridge MS et al. N Engl J Med
2011;364:1293-1304



The NEW ENGLAND
JOURNAL of MEDICINE

From: **Mortality Related to Severe Sepsis and Septic Shock Among Critically Ill Patients in Australia and New Zealand, 2000-2012**

JAMA. 2014;311(13):1308-1316. doi:10.1001/jama.2014.2637

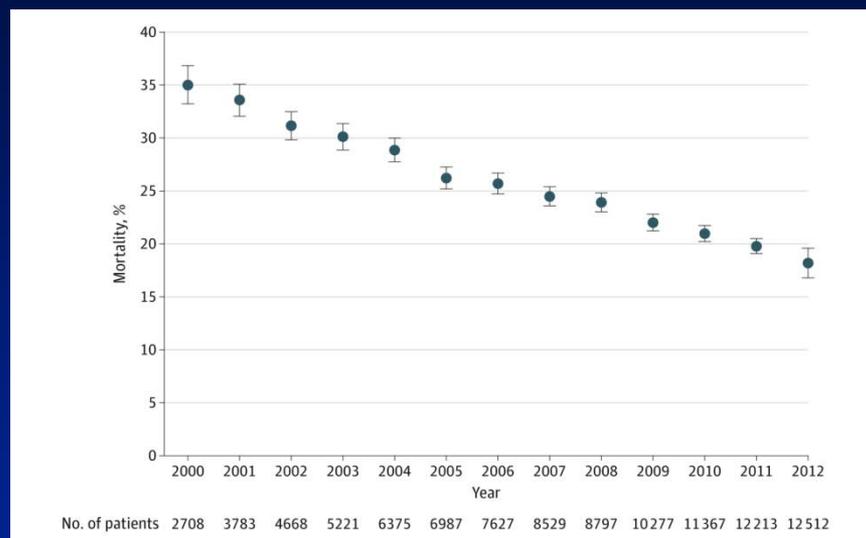


Figure Legend:

Mean Annual Mortality in Patients With Severe Sepsis Error bars indicate 95% CI.

Long-Term Quality of Life Among Survivors of Severe Sepsis: Analyses of Two International Trials*

Sachin Yende, MD, MS^{1,2}; Shamy Austin, PhD, MHA^{1,3}; Andrew Rhodes, MD⁴; Simon Finfer, MD, FCICM⁵; Steven Opal, MD⁶; Taylor Thompson, MD⁷; Fernando A. Bozza, MD, PhD^{1,8}; Steven P. LaRosa, MD⁹; V. Marco Ranieri, MD¹⁰; Derek C. Angus, MD, MPH¹

*See also p. 1603.

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The contents of this article do not represent the views of the U.S. Department of Veterans Affairs or the United States Government.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (<http://journals.lww.com/ccmjournal>).

Dr. Rhodes consulted for, received support for travel from, and received support for participation in review activities from Eli Lilly (Dr. Rhodes was paid by Eli Lilly to act on the SSC of the PROWESS-SHOCK Trial). He lectured for LiDCO (lecture fees). Dr. Opal's institution received funding from Eisai (provided a grant to institution to run the clinical coordinating center for the phase 3 study of Eritoran), Ferring (for clinical coordinating center), and Cardeas. He disclosed other support from Arsanis (advisory committee), Anidis (consultant), BioAegis (consultant), Glaxo Smith Kline (institutional grant), Ataxbio (institutional grant), Immunexpress (consultant), Battelle (consultant), Bekton-Dickenson (consultant), and Spectral, Partek, and Achaogen (data monitoring board). Dr. Thompson consulted for Lilly (see electronic supplement to PMID: 22616830 for details) and received support for travel from Lilly. Dr. Bozza is employed by Oswaldo Cruz Foundation, Ministry of Health, Brazil. Dr. Bozza and his institution received grant support from CNPq, FAPERJ, CAPES (Brazilian Agencies for Research), the National Institutes of Health, Wellcome Trust, and Biomeieux Foundation. Dr. LaRosa received support for participation in review activities from Eisai (clinical evaluation committee—A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis [ACCESS] trial) and consulted (scientific advisory board). His institution received

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grant support from Eisai (for access trial). Dr. Angus served as a board member for data and safety monitoring board PROWESS-SHOCK Trial and consulted for Eisai for ACCESS, Ferring Pharmaceuticals, MedImmune, and GlaxoSmithKline. He received grant support from Eisai. The remaining authors have disclosed that they do not have any potential conflicts of interest.

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Objectives: To describe the quality of life among sepsis survivors.

Design: Secondary analyses of two international, randomized clinical trials (A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis [derivation cohort] and PROWESS-SHOCK [validation cohort]).

Setting: ICUs in North and South America, Europe, Africa, Asia, and Australia.

Patients: Adults with severe sepsis. We analyzed only patients who were functional and living at home without help before sepsis hospitalization ($n = 1,143$ and 987 from A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis and PROWESS-SHOCK, respectively).

Interventions: None.

Measurements and Main Results: In A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis and PROWESS-SHOCK, the average age of patients living at home independently was 63 and 61 years; 400 (34.9%) and 298 (30.2%) died by 6 months. In A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis, 580 patients had a quality of life measured using EQ-5D at 6 months. Of these, 41.6% could not live independently (22.7% were home but required help, 5.1% were in nursing home or rehabilitation facilities, and 5.3% were in acute care hospitals). Poor quality of life at 6 months, as evidenced by problems in mobility, usual activities, and self-care domains were reported in 37.4%, 43.7%, and 20.5%, respectively, and the high incidence of poor quality of life was also seen in patients in PROWESS-SHOCK. Over 45% of patients with mobility and self-care problems at 6 months in A Controlled Comparison of Eritoran and placebo in patients with Severe Sepsis died or reported persistent problems at 1 year.

Conclusions: Among individuals enrolled in a clinical trial who lived independently prior to severe sepsis, one third had died and of those who survived, a further one third had not returned to independent living by 6 months. Both mortality and quality of life should

Long-term Cognitive Impairment and Functional Disability Among Survivors of Severe Sepsis

Theodore J. Iwashyna, MD, PhD

E. Wesley Ely, MD, MPH

Dylan M. Smith, PhD

Kenneth M. Langa, MD, PhD

COGNITIVE IMPAIRMENT AND physical disability are major health burdens and drivers of health care costs. The onset of disability is associated with worsened mortality¹ and substantial increases in medical costs over subsequent years,² including a disproportionate strain on Medicaid and Medicare. Both cognitive and physical disability impose yet further burdens on families and informal caregivers.³ Irreversible cognitive and physical impairment following acute illnesses are particularly feared outcomes and weigh heavily on patient decision making.⁴

Hundreds of thousands of patients endure severe sepsis each year in the United States.⁵ It has been suspected that many are discharged with a new—but poorly defined—constellation of cognitive and functional impairments,⁶ which may explain their reduced quality of life.⁷ Even hospitalizations for less severe illness often result in a period of functional disability⁸ and may hasten the progression of dementia.^{9,10} Long-term cognitive and functional declines have been shown among survivors of other critical illnesses, but these declines may be partially preventable.¹¹⁻¹⁴ Although severe sepsis is the most common non-cardiac cause of critical illness,^{8,15} the long-term impact of severe sepsis on cognitive and physical functioning is unknown.

See also p 1833 and Patient Page.

Context Cognitive impairment and functional disability are major determinants of caregiving needs and societal health care costs. Although the incidence of severe sepsis is high and increasing, the magnitude of patients' long-term cognitive and functional limitations after sepsis is unknown.

Objective To determine the change in cognitive impairment and physical functioning among patients who survive severe sepsis, controlling for their pre-sepsis functioning.

Design, Setting, and Patients A prospective cohort involving 1194 patients with 1520 hospitalizations for severe sepsis drawn from the Health and Retirement Study, a nationally representative survey of US residents (1998-2006). A total of 9223 respondents had a baseline cognitive and functional assessment and had linked Medicare claims; 516 survived severe sepsis and 4517 survived a nonsepsis hospitalization to at least 1 follow-up survey and are included in the analysis.

Main Outcome Measures Personal interviews were conducted with respondents or proxies using validated surveys to assess the presence of cognitive impairment and to determine the number of activities of daily living (ADLs) and instrumental ADLs (IADLs) for which patients needed assistance.

Results Survivors' mean age at hospitalization was 76.9 years. The prevalence of moderate to severe cognitive impairment increased 10.6 percentage points among patients who survived severe sepsis, an odds ratio (OR) of 3.34 (95% confidence interval [CI], 1.53-7.25) in multivariable regression. Likewise, a high rate of new functional limitations was seen following sepsis: in those with no limits before sepsis, a mean 1.57 new limitations (95% CI, 0.99-2.15); and for those with mild to moderate limitations before sepsis, a mean of 1.50 new limitations (95% CI, 0.87-2.12). In contrast, nonsepsis general hospitalizations were associated with no change in moderate to severe cognitive impairment (OR, 1.15; 95% CI, 0.80-1.67; *P* for difference vs sepsis = .01) and with the development of fewer new limitations (mean among those with no limits before hospitalization, 0.48; 95% CI, 0.39-0.57; *P* for difference vs sepsis < .001 and mean among those with mild to moderate limits, 0.43; 95% CI, 0.23-0.63; *P* for difference = .001). The declines in cognitive and physical function persisted for at least 8 years.

Conclusions Severe sepsis in this older population was independently associated with substantial and persistent new cognitive impairment and functional disability among survivors. The magnitude of these new deficits was large, likely resulting in a pivotal downturn in patients' ability to live independently.

JAMA. 2010;304(16):1787-1794

www.jama.com

We studied whether an incident episode of severe sepsis increased the odds of subsequent worsened cognitive impairment and functional disability among sur-

vivors. We took advantage of a nationally representative ongoing cohort study of older Americans that included detailed information from personal surveys and

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Recovery after critical illness in patients aged 80 years or older: a multi-center prospective observational cohort study

Intensive Care Units (ICUs). The objective of this study was to describe 12-month outcomes of these patients and determine which characteristics are associated with a return to baseline physical function 1 year later.

Methods: In this prospective cohort study in 22 Canadian hospitals, we recruited 610 patients aged 80 years or older who were admitted to ICU for at least 24 h. At baseline, we completed a comprehensive geriatric assessment and followed patients to determine 12-month survival and physical function. Our primary outcome was physical recovery from critical illness at 12 months, defined as being alive with Short Form-36

physical function score of at least 10 points, and not 10 or more points below baseline. We used regression analysis to examine factors associated with physical recovery. **Results:** Patients were on average 84 years old (range 80–99). **Mortality** was 14 % in ICU, 26 % in hospital and 44 % at 12 months after admission. Of 505 patients evaluable at 12 months, 26 % achieved physical recovery. In the multivariable model, physical recovery was significantly associated with younger age, lower APACHE II score, lower Charlson comorbidity score, lower frailty index, lower baseline physical function score, and specific admission

diagnoses. **Conclusions:** One-quarter of patients aged 80 years or older who are admitted to ICU survived and returned to baseline levels of physical function at 1 year. Routine assessment of baseline physical function and frailty status could aid in prognostication and informed decision-making for very old critically ill patients. (ClinicalTrials.gov number NCT01293708).

Keywords Outcome assessment · Critical illness · Physical function · Follow up study · Frailty · Aged 80 and older



After all, there are worse things in life than death. If you've ever spent an evening with an insurance salesman, you know what I'm talking about.

(Woody Allen)

Association between frailty and short- and long-term outcomes among critically ill patients: a multicentre prospective cohort study

Sean M. Bagshaw MD, H. Thomas Stelfox MD, Robert C. McDermid MD, Darryl B. Rolfson MD, Ross T. Tsuyuki PharmD, Nadia Baig BSc, Barbara Artiuch MD, Quazi Ibrahim MSc, Daniel E. Stollery MD, Ella Rokosh MD, Sumit R. Majumdar MD

ABSTRACT

Background: Frailty is a multidimensional syndrome characterized by loss of physiologic and cognitive reserves that confers vulnerability to adverse outcomes. We determined the prevalence, correlates and outcomes associated with frailty among adults admitted to intensive care.

Methods: We prospectively enrolled 421 critically ill adults aged 50 or more at 6 hospitals across the province of Alberta. The primary exposure was frailty, defined by a score greater than 4 on the Clinical Frailty Scale. The primary outcome measure was in-hospital mortality. Secondary outcome measures included adverse events, 1-year mortality and quality of life.

Results: The prevalence of frailty was 32.8% (95% confidence interval [CI] 28.3%–37.5%). Frail patients were older, were more likely to be female, and had more comorbidities and greater functional dependence than those who were not frail. In-hospital mortality was

higher among frail patients than among non-frail patients (32% v. 16%; adjusted odds ratio [OR] 1.81, 95% CI 1.09–3.01) and remained higher at 1 year (48% v. 25%; adjusted hazard ratio 1.82, 95% CI 1.28–2.60). Major adverse events were more common among frail patients (39% v. 29%; OR 1.54, 95% CI 1.01–2.37). Compared with nonfrail survivors, frail survivors were more likely to become functionally dependent (71% v. 52%; OR 2.25, 95% CI 1.03–4.89), had significantly lower quality of life and were more often readmitted to hospital (56% v. 39%; OR 1.98, 95% CI 1.22–3.23) in the 12 months following enrolment.

Interpretation: Frailty was common among critically ill adults aged 50 and older and identified a population at increased risk of adverse events, morbidity and mortality. Diagnosis of frailty could improve prognostication and identify a vulnerable population that might benefit from follow-up and intervention.

Competing interests: Ross Tsuyuki has served on advisory boards for Bristol-Myers Squibb, PharmaSmart International and Abbott Laboratories, and a data monitoring board for dabigatran studies for Boehringer Ingelheim; he has received consultant fees from Merck; and his institution has received grants from Sanofi and AstraZeneca. No competing interests were declared by the other authors.

This article has been peer reviewed.

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CMAJ 2014, DOI:10.1503/cmaj.130639

Appendix 2: Clinical Frailty Scale

Clinical Frailty Scale*



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

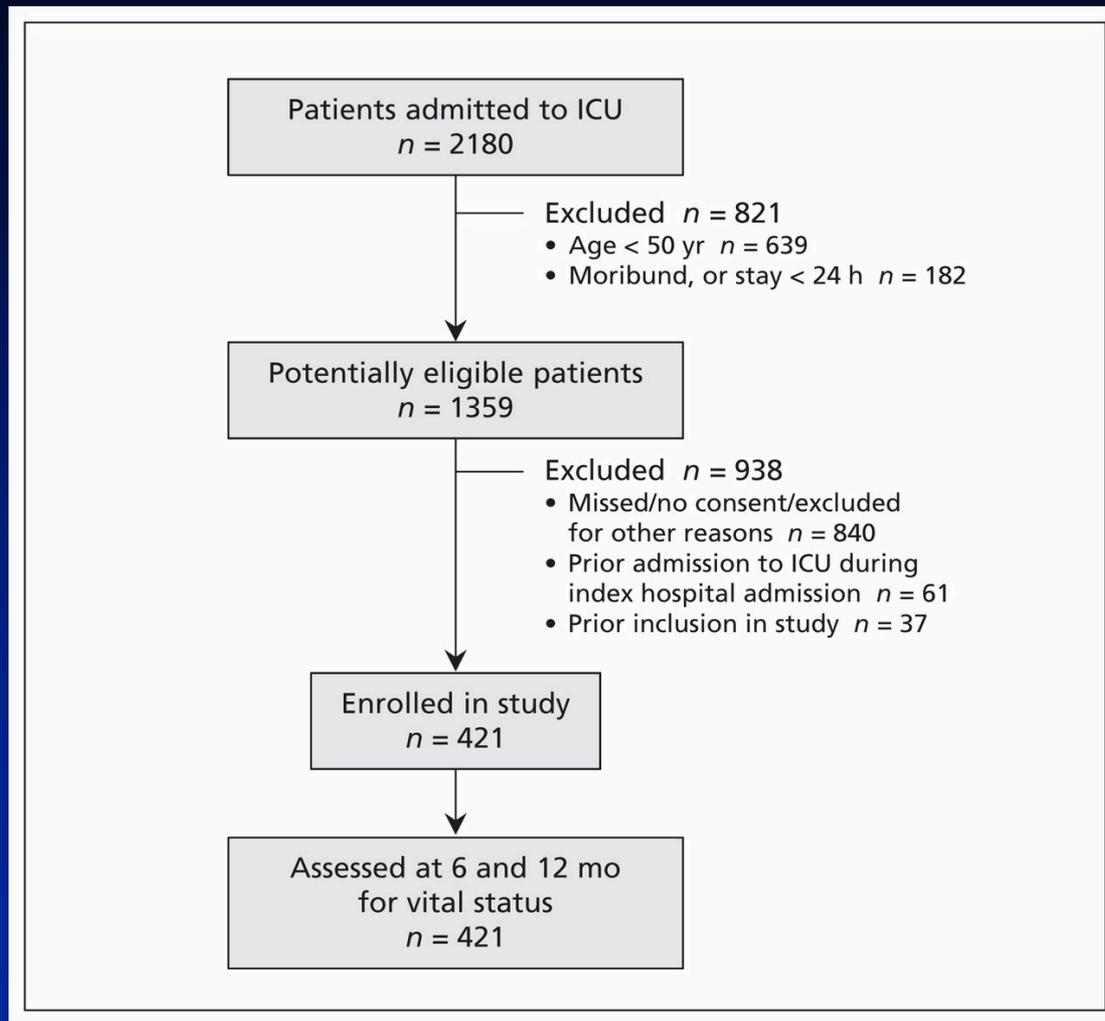
The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

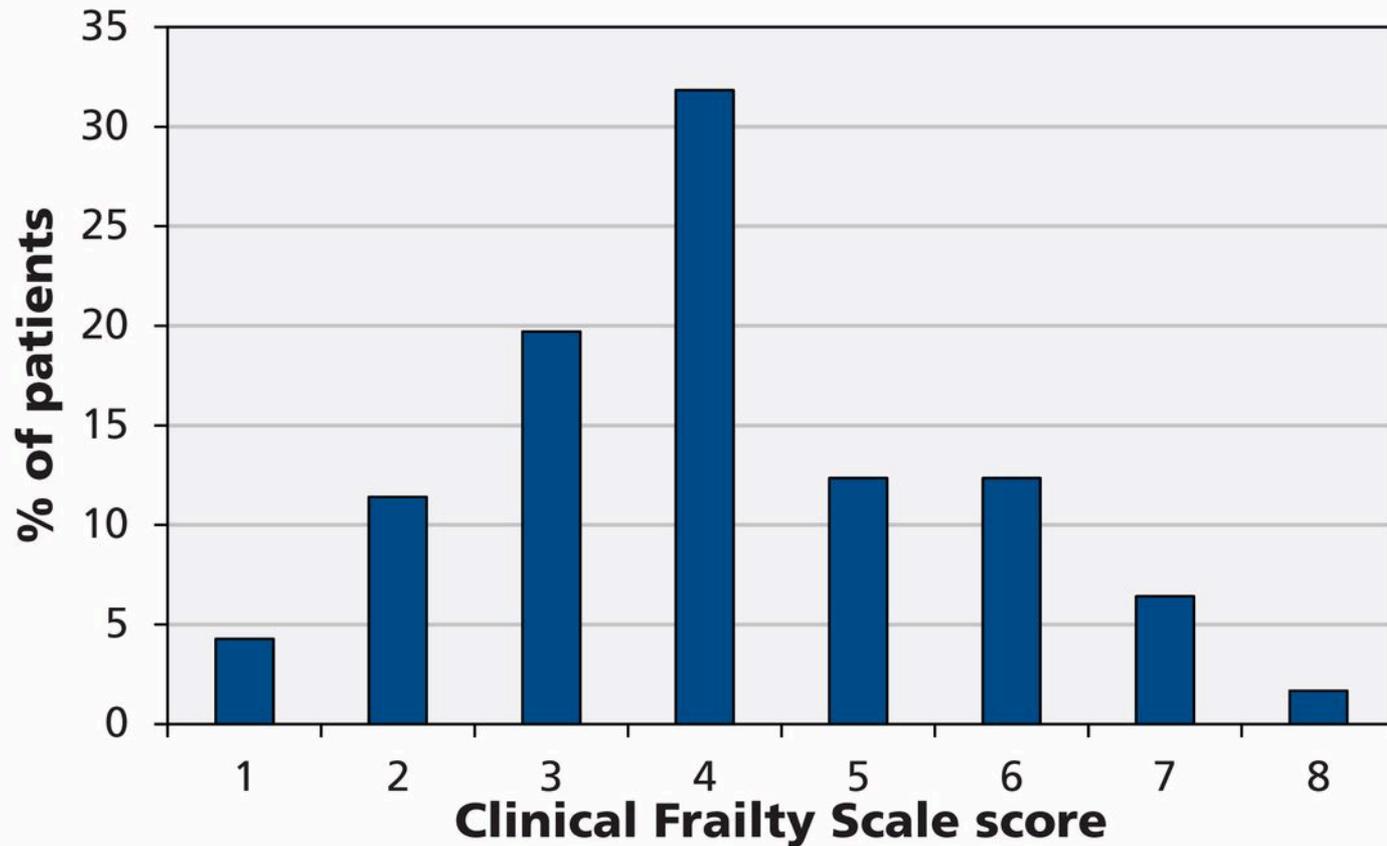
* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

Selection of critically ill patients for the study cohort.



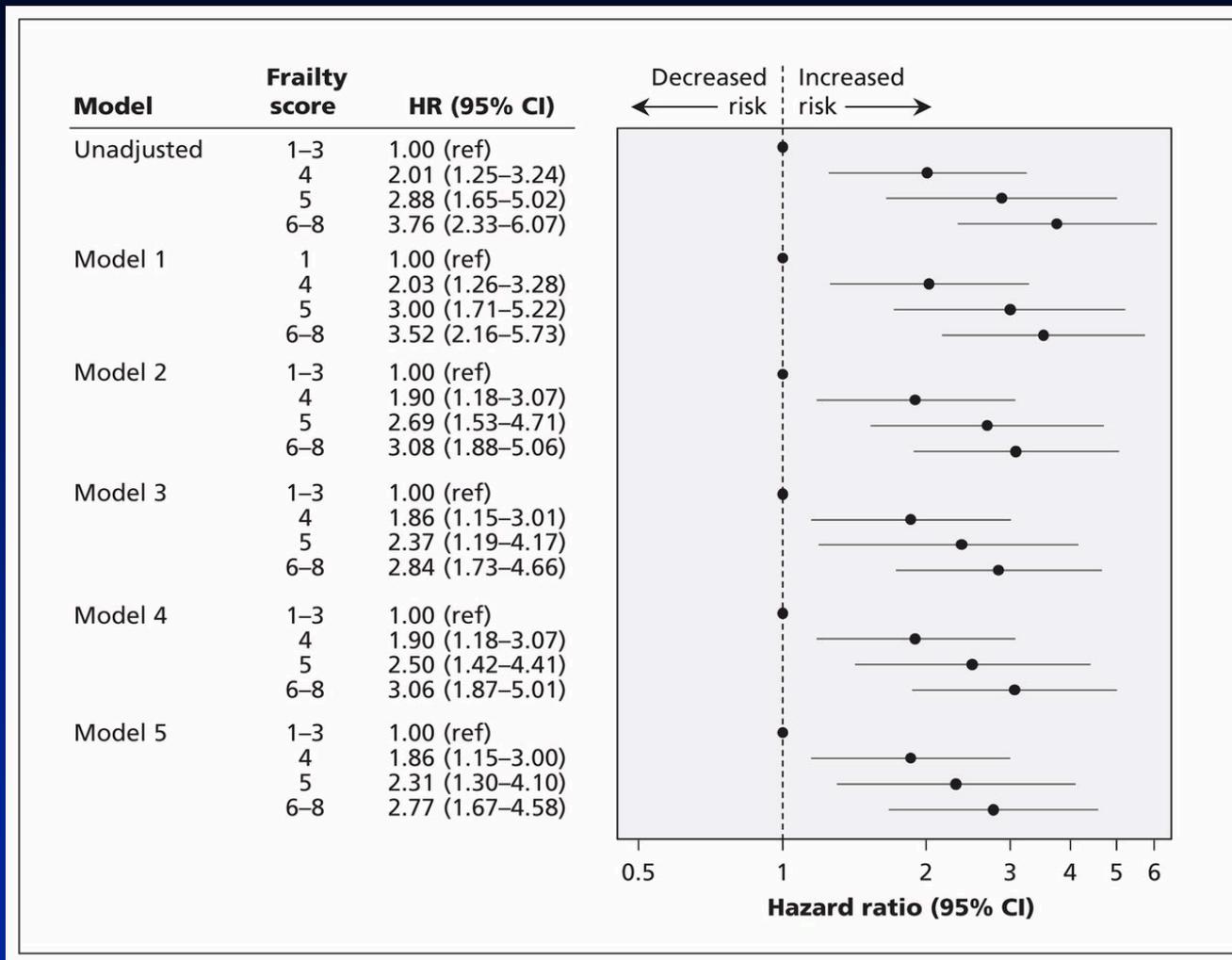
Bagshaw S M et al. CMAJ 2014;186:E95-E102

Distribution of Clinical Frailty Scale scores and prevalence of frailty (score > 4) among the participants.



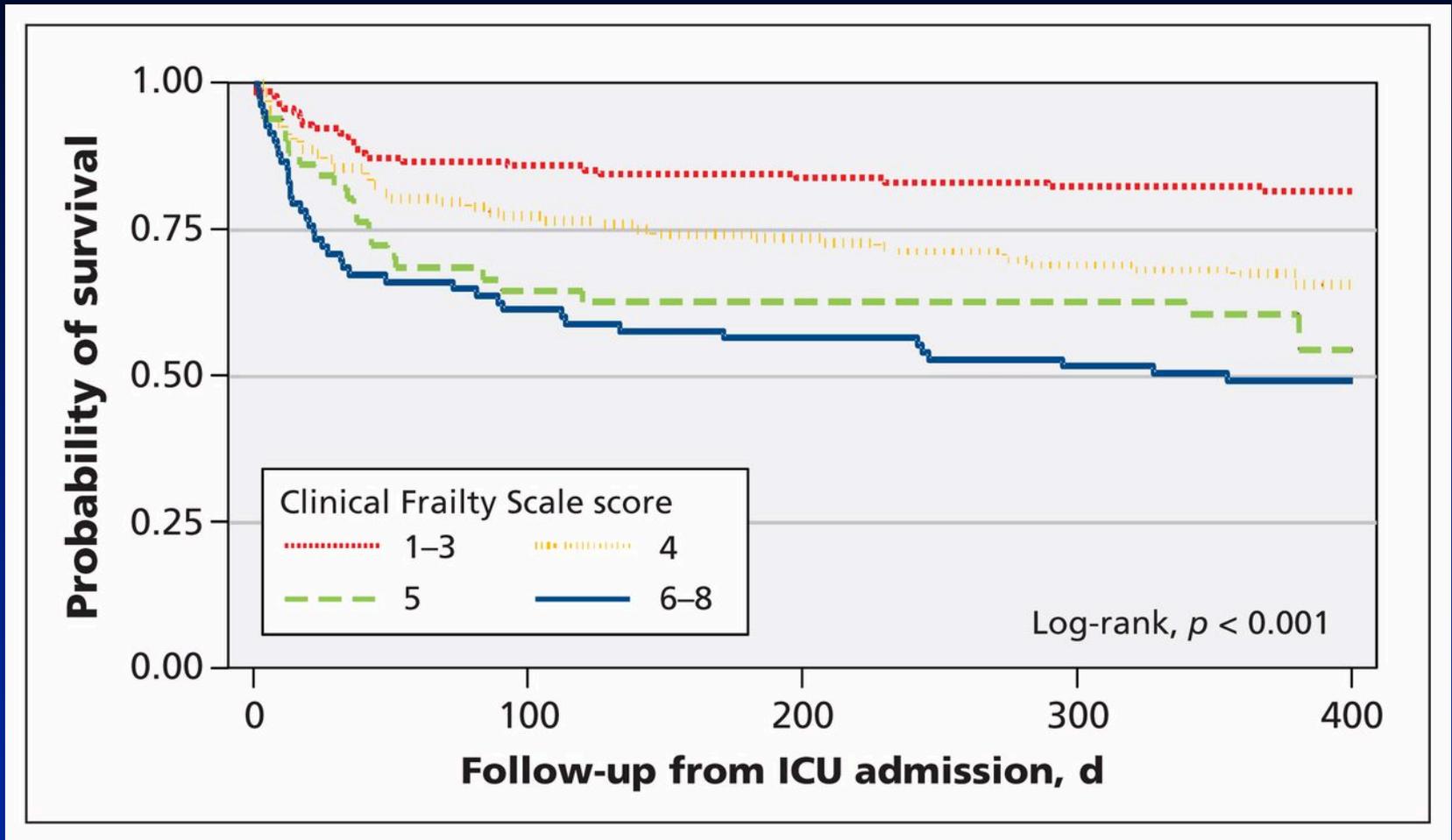
Bagshaw S M et al. CMAJ 2014;186:E95-E102

Adjusted hazard ratios for death within 12 months after admission to an intensive care unit, stratified by Clinical Frailty Scale score (score > 4 indicates frailty).



Bagshaw S M et al. CMAJ 2014;186:E95-E102

Kaplan–Meier survival curves stratified by Clinical Frailty Scale score.



Bagshaw S M et al. CMAJ 2014;186:E95-E102

One-Year Outcomes in Caregivers of Critically Ill Patients

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ABSTRACT

BACKGROUND

Few resources are available to support caregivers of patients who have survived critical illness; consequently, the caregivers' own health may suffer. We studied caregiver and patient characteristics to determine which characteristics were associated with caregivers' health outcomes during the first year after patient discharge from an intensive care unit (ICU).

METHODS

We prospectively enrolled 280 caregivers of patients who had received 7 or more days of mechanical ventilation in an ICU. Using hospital data and self-administered questionnaires, we collected information on caregiver and patient characteristics, including caregiver depressive symptoms, psychological well-being, health-related quality of life, sense of control over life, and effect of providing care on other activities. Assessments occurred 7 days and 3, 6, and 12 months after ICU discharge.

RESULTS

The caregivers' mean age was 53 years, 70% were women, and 61% were caring for a spouse. A large percentage of caregivers (67% initially and 43% at 1 year) reported high levels of depressive symptoms. Depressive symptoms decreased at least partially with time in 84% of the caregivers but did not in 16%. Variables that were significantly associated with worse mental health outcomes in caregivers were younger age, greater effect of patient care on other activities, less social support, less sense of control over life, and less personal growth. No patient variables were consistently associated with caregiver outcomes over time.

CONCLUSIONS

In this study, most caregivers of critically ill patients reported high levels of depressive symptoms, which commonly persisted up to 1 year and did not decrease in some caregivers. (Funded by the Canadian Institutes of Health Research and others; ClinicalTrials.gov number, NCT00896220.)

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Cost to relatives

- **Financial: US \$642 billion annually.
Canada \$27 billion annually.**

More than 1/2 the patients who have received prolonged mechanical ventilation during a stay in ICU and survive to discharge continue to require assistance from a care-giver one year after ICU discharge.

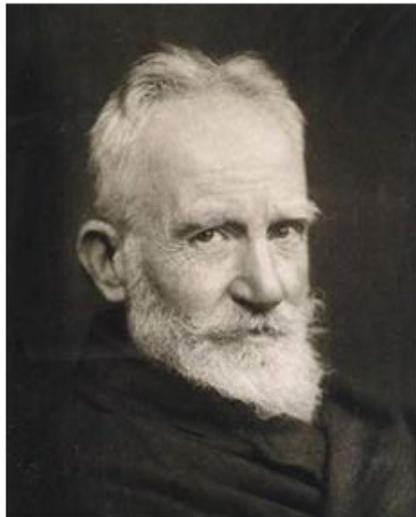


Long-term Outcomes after Critical Illness. The Best Predictor of the Future is the Past.

Brian Cuthbertson and Hannah Wunsch . AJRCCM 2016.

The single biggest problem in communication is the illusion that it has taken place.

-- George Bernard Shaw



***Patient centred.
Attitudes, values and beliefs.
Burden of ongoing care.***

Is our current system of the end of life care working?

- Major area of disputes, complaints and media attention

DESPITE

- Significant health expenditure
 - 50% die in acute care hospitals
 - 30% of Medicare expenditure (US) is for patients in last year of life- 40% in last month of life

Courts and decisions

- **72 y.o. out of hospital cardiac arrest**
- **25 minutes down time**
- **GCS 3 at 3 weeks**
- **Breathing spontaneously – *not brain dead***
- **Medical consensus that no real prospect of significant recovery.**
- **Family wanted ventilation for 6 months**
- ***Mesiha v Southeastern Sydney Health Service (2004)***

Patient's current state

- **Mechanically ventilated through a tube**
- **Fed and hydrated through a tube**
- **Urine removed through a tube**
- **Faeces removed through a tube**
- **Saliva removed through a (suction) tube**
- **Eyes taped to prevent corneal ulceration**

Courts, doctors and decisions

...current treatment is futile...also will be burdensome and intrusive...Court is in no better position to make a determination of future treatment than are those who are principally under the duty to make such a decision...withdrawal of treatment may put his life in jeopardy but only to the extent of bringing forward what I believe to be inevitable in the short term.

Howie

Who makes the decisions?

- 30 y.o. man
- Thalassaemia major (i.e.homozygote)
- *Paediatrics* → *haematology* → *cardiology*
- BP 90/40 on dobutamine
- Oliguric
- *Cardiology* → *nephrology* → *intensive care*
- 'Patient and family want everything done'

What is 'everything'?

Do you want everything done?

i.e. treatment, comfort, care, life.



Good

Do you want nothing done?

i.e. abandonment, pain, suffering, death.



Bad

no brainer

Everything that is appropriate?

- Pain control
- Relief of suffering
- Facilitating maximal possible functional capacity
- Focus on physical, psychological, spiritual and intellectual needs of patient

- Good (*palliative*) medicine

ADVANCE CARE DIRECTIVES BILL
House of Assembly - Wednesday, 17 October 2012,
The Hon. J.D. Hill

What is appropriate healthcare to be offered in particular circumstances is to be determined by health practitioners according to their clinical expertise and judgment. This is consistent with a well accepted common law principle of health care that a person can consent to treatment that is offered, and refuse treatment that is offered, but cannot demand treatment that is not offered.

Part 2—Amendment of *Consent to Medical Treatment and Palliative Care Act 1995*

(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision—

(a) is under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state (whether or not the patient or the patient's representative has requested that such measures be used or continued); and

(b) must, if the patient or the patient's representative so directs, withdraw life sustaining measures from the patient.

6—Health practitioner cannot be compelled to provide particular health care

(1) Nothing in this Act authorises the making of—

(a) a provision of an advance care directive; or

(b) a decision by a substitute decision-maker under an advance care directive; or

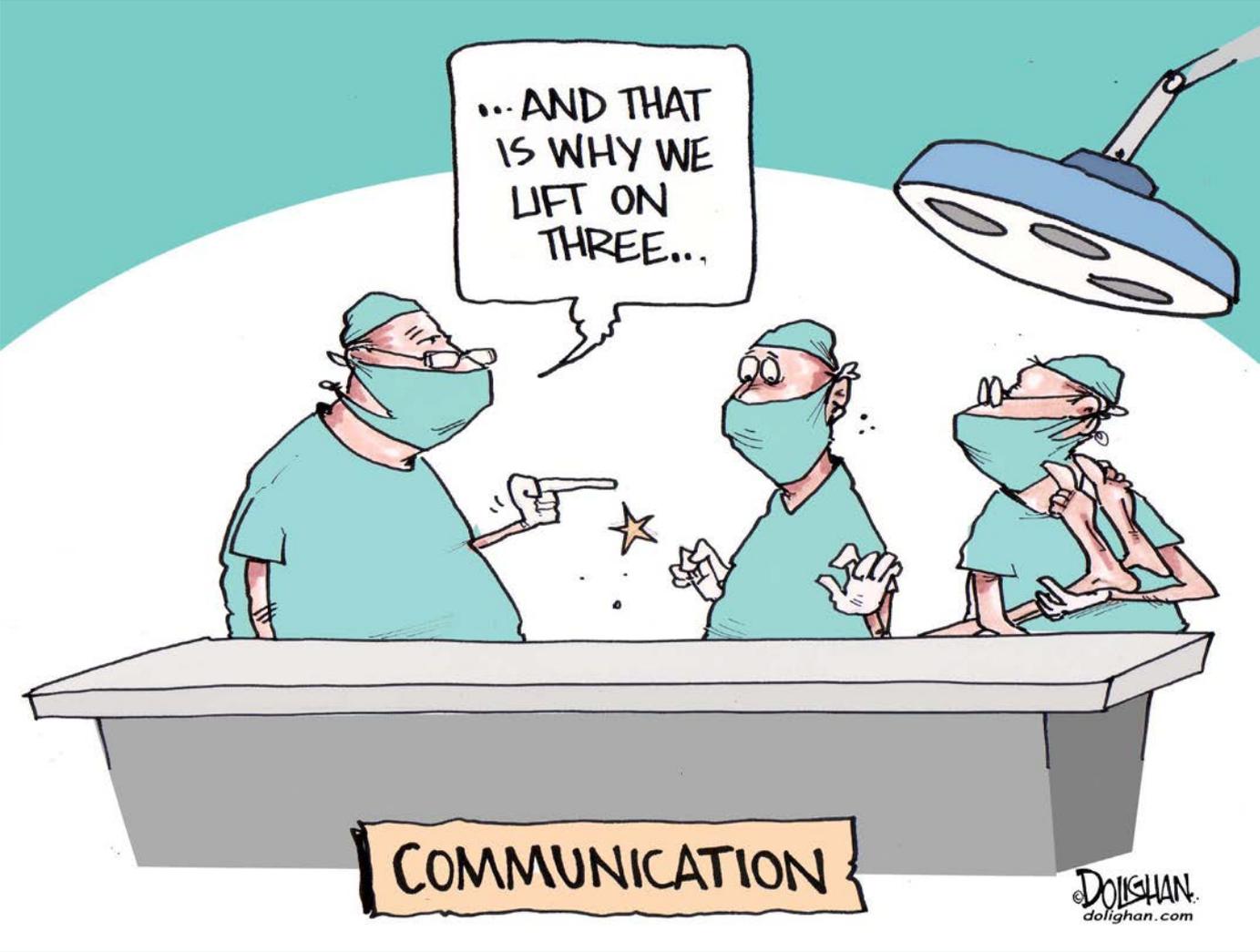
(c) an order made under Part 7,

that purports to compel a health practitioner to provide a particular form of health care to a person.

Note—

Whilst a person can indicate his or her wishes in respect of the health care he or she wishes to receive, ultimately the question of what form of health care should be provided to a patient is a matter for the health practitioner to decide

(however, a person is entitled to refuse health care of any kind, or to require it to be stopped, including health care that saves or prolongs his or her life).



ANZICS Statement on End-of-Life Care for the Critically Ill

Principles of End-of-Life-Care

“The success of intensive care is not, therefore, to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.”

G.R Dunstan, University of London, 1984

Should ICU make the decisions??

