Palliative Care and Stroke: An Emerging Field

Robert Holloway, MD, MPH

October 23, 2015

MEDICINE *of* THE HIGHEST ORDER

UNIVERSITY *of* ROCHESTER MEDICAL CENTER

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Outline

Palliative Care

Palliative Care and Stroke in the Literature

Integration of Primary and Specialty Palliative Care

Palliative Care Version 2.0

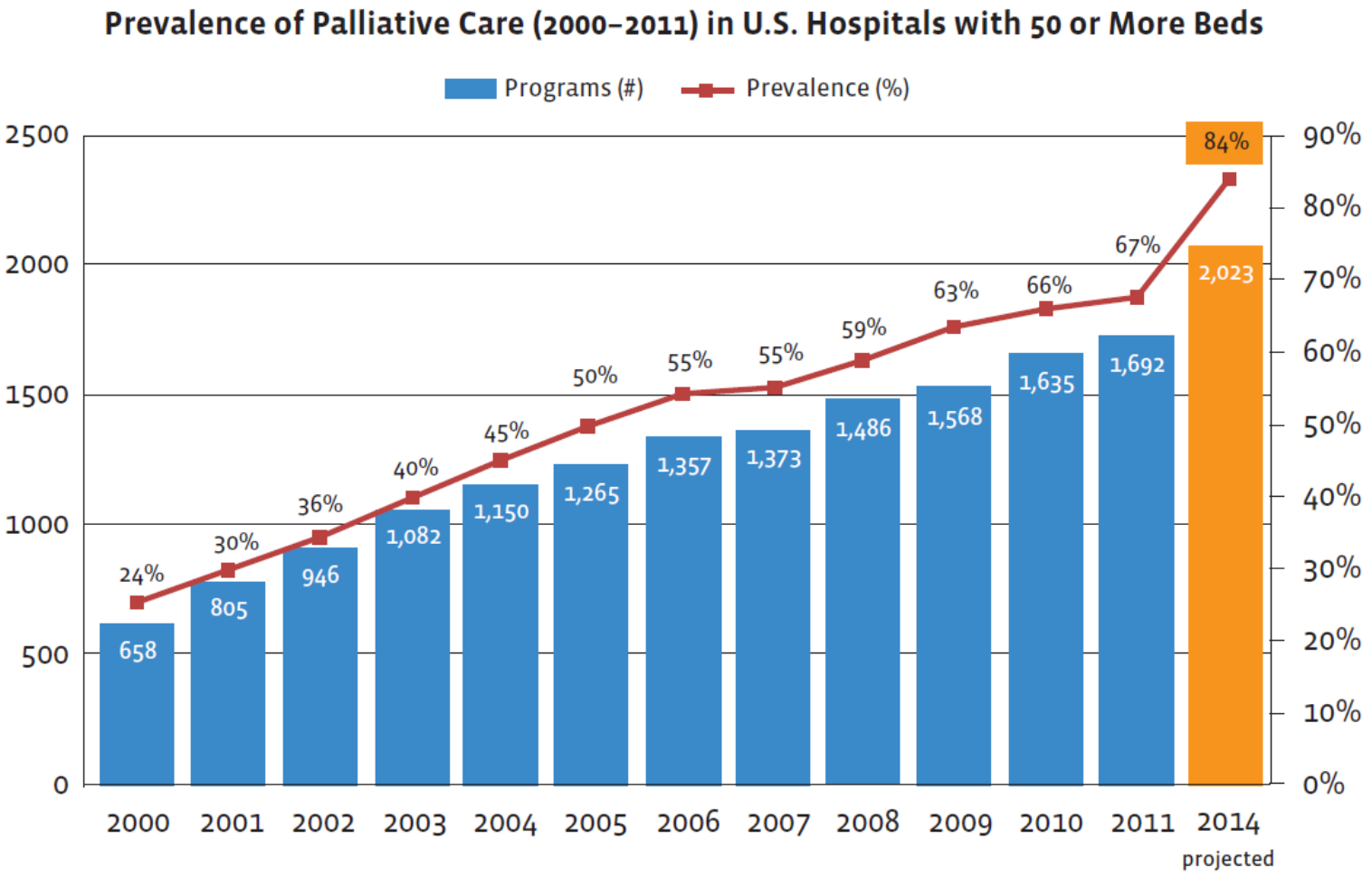
Palliative Care

Palliative care *means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.*

Palliative Care Philosophy

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and nonpalliative healthcare providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and death.

Palliative Care in the U.S.



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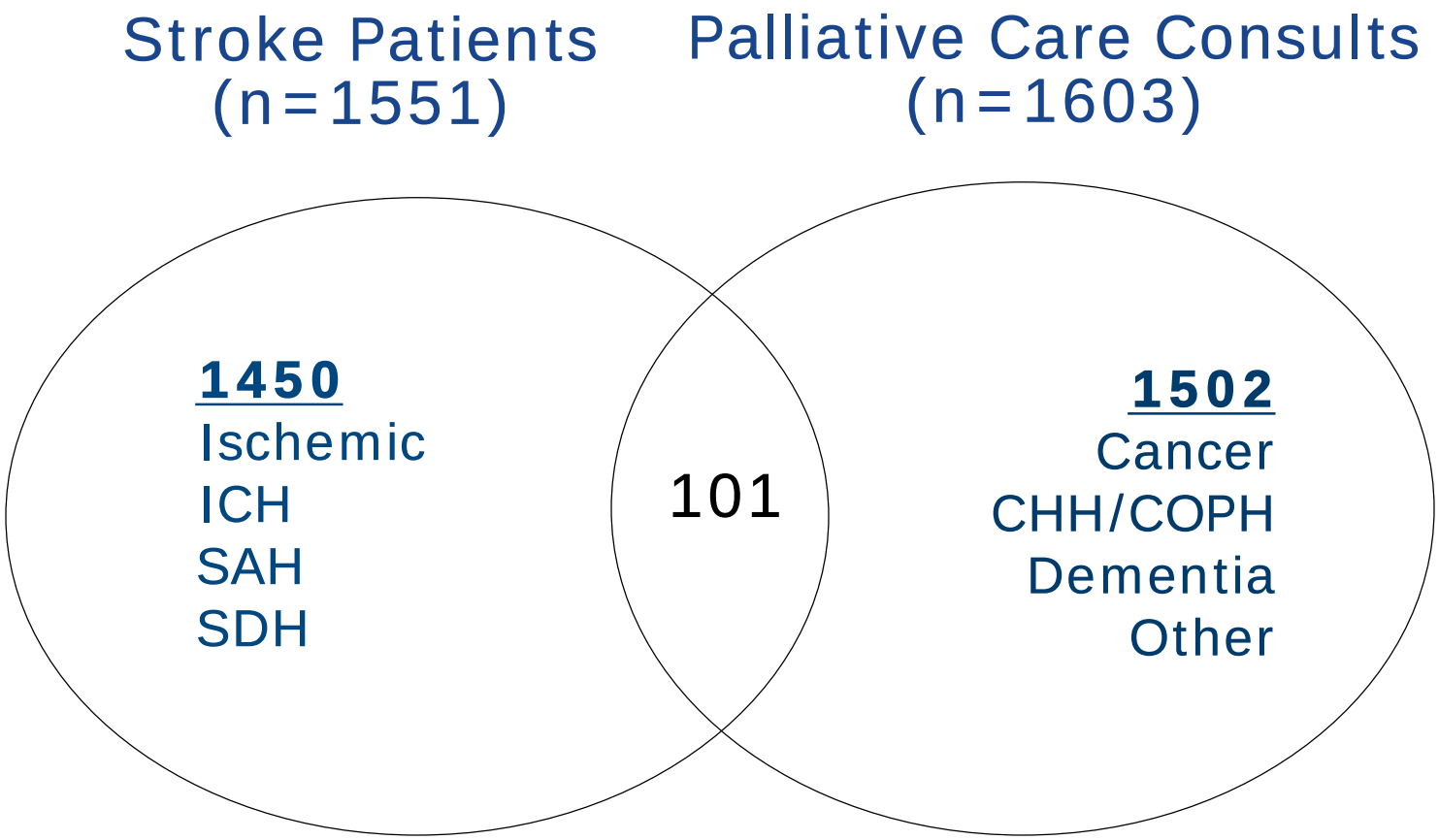
Palliative Care in Stroke and the Literature

1. Burton CR, Payne S, Addington-Hall J, Jones A. **The palliative care needs of acute stroke patients: a prospective study of hospital admissions**. Age Ageing. 2010;39:554–559
2. Mead GE, Cowey E, Murray SA. **Life after stroke—is palliative care relevant? A better understanding of illness trajectories after stroke may help clinicians identify patients for a palliative approach to care**. Int J Stroke. 2013;8:447–448
3. Stevens T, Payne SA, Burton C, Addington-Hall J, Jones A. **Palliative care in stroke: a critical review of the literature. Palliat Med**. 2007;21:323–33
4. Wee B, Adams A, Eva G. **Palliative and end-of-life care for people with stroke**. Curr Opin Support Palliat Care. 2010;4:229–232
5. Burton CR, Payne S. **Integrating palliative care within acute stroke services: developing a programme theory of patient and family needs, preferences and staff perspectives**. BMC Palliat Care. 2012;11:22
6. Holloway RG, Ladwig S, Robb J, Kelly A, Nielsen E, Quill TE. **Palliative care consultations in hospitalized stroke patients**. J Palliat Med. 2010;13:407–412
7. Chahine LM, Malik B, Davis M. **Palliative care needs of patients with neurologic or neurosurgical conditions.** Eur J Neurol. 2008;15:1265–1272
8. Eastman P, McCarthy G, Brand CA, Weir L, Gorelik A, Le B. **Who, why and when: stroke care unit patients seen by a palliative care service within a large metropolitan teaching hospital. BMJ Support Palliat Care**. 2013;3:77–83
9. Addington-Hall J, Lay M, Altmann D, McCarthy M. **Symptom control, communication with health professionals, and hospital care of stroke patients in the last year of life as reported by surviving family, friends, and officials**. Stroke. 1995;26:2242–2248

Palliative Care Consultations in Hospitalized Stroke Patients (J Palliat Med 2010)



Demographics of Stroke Patients with and without a Palliative Care Consult

	PC Consult n = 101	No Consult n = 1450
Mean age, years	72.4	64.7
Male, %	48	50
Non-white, %	11	25
Inpatient death, %	79	11
Median LOS	14	5

Of these 101 consults, how many involved goals of care discussion around artificial nutrition and feeding tubes?

A. 5

B. 22

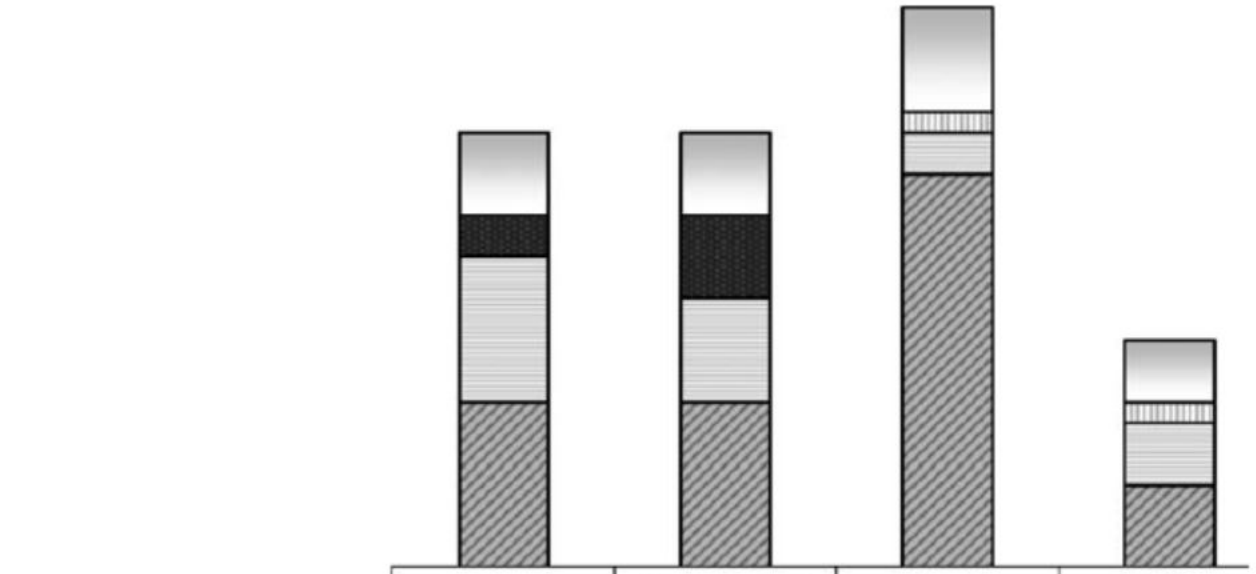
C. 47

D. 71

E. 94

Goals of Care Discussion in Stroke Patients with PC Consult

Topic Area	N = 101
Artificial nutrition/feeding tubes	47
Natural nutrition	20
Tracheostomy	18
Intravenous fluids	14
Antibiotics	12
Neurosurgical procedures	8



	Ischemic	Intracerebral	SAH	Subdural
Other	4	4	5	3
Brain Death	0	0	1	1
Withhold Nutrition	2	4	0	0
Withhold Mech. Vent	7	5	2	3
Terminal Extubation	8	8	19	4

FIG. 1. Mode of in-hospital death of palliative care stroke patients. Other medical conditions contributing to death or discharge to hospice included cancer (4 cases), myocardial infarction (1 case), pulmonary embolism (1 case), withdrawal of hemodialysis (1 case), and chronic progressive neurologic dysfunction (1 case), multiple causes, indeterminate (8 cases).

Conclusions

Stroke patients with a PC consult differ from other consults seen on a hospital PC consult service.

Stroke patients were more often consulted for goals of care /end-of-life decisions and less for symptom management.

Inpatient stroke mortality was higher than other diagnoses seen by the PC service – and most common mode of death was compassionate extubation.

The majority of dying stroke patients (74%) and those discharged to hospice (57%) did not have a PC consult.

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Primary versus Specialty Palliative Care
(NEJM 2013; 368:1173)

Primary Palliative Care

Basic management of pain and symptoms

Basic management of depression and anxiety

Basic discussions about
- Prognosis
- Goals of treatment
- Suffering
- Code Status

Specialty Palliative Care

Management of refractory pain or other symptoms

Management of more complex depression, anxiety, grief, and existential distress

Assistance with conflict resolution regarding goals or methods of treatment

Assistance in addressing cases of near futility

AHA/ASA Scientific Statement

Palliative and End-of-Life Care in Stroke

A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

Endorsed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, The American Academy of Hospice and Palliative Medicine, American Geriatrics Society, Neurocritical Care Society, American Academy of Physical Medicine and Rehabilitation, and American Association of Neuroscience Nurses

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Kevin N. Sheth, MD, FAHA; Darin B. Zahuranec, MD, MS, FAHA; Gregory J. Zipfel, MD;
Richard D. Zorowitz, MD, FAHA; on behalf of the American Heart Association Stroke Council,
Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology

***Background and Purpose*—**The purpose of this statement is to delineate basic expectations regarding primary palliative care competencies and skills to be considered, learned, and practiced by providers and healthcare services across hospitals and community settings when caring for patients and families with stroke.

***Methods*—**Members of the writing group were appointed by the American Heart Association Stroke Council's Scientific Statement Oversight Committee and the American Heart Association's Manuscript Oversight Committee. Members were chosen to reflect the diversity and expertise of professional roles in delivering optimal palliative care. Writing group members were assigned topics relevant to their areas of expertise, reviewed the appropriate literature, and drafted manuscript content and recommendations in accordance with the American Heart Association's framework for defining classes and level of evidence and recommendations.

***Results*—**The palliative care needs of patients with serious or life-threatening stroke and their families are enormous: complex decision making, aligning treatment with goals, and symptom control. Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of illness. To optimally deliver primary palliative care, stroke systems of care and provider teams should (1) promote and practice patient- and family-centered care; (2) effectively estimate prognosis; (3) develop appropriate goals of care; (4) be familiar with the evidence for common stroke decisions with end-of-life implications; (5) assess and effectively manage emerging stroke symptoms; (6) possess experience with palliative treatments at the end of life; (7) assist with care coordination, including referral to a palliative care specialist or hospice if necessary; (8) provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated; and (9) actively participate in continuous quality improvement and research.

***Conclusions*—**Addressing the palliative care needs of patients and families throughout the course of illness can complement

Table 1. Primary Palliative Care Skills for the Stroke Specialist

	Primary Stroke Palliative Care Skills
Pain and symptoms	Recognize early signs of pain, depression, anxiety, delirium
	Basic symptom management skills
Communication skills	Communicate with empathy and compassion
	Authentic and active listening
	Narrative competence to elicit the patient's story
	Effectively elicit individual treatment goals (see Goals of care)
	Effectively share information with the patient and family using terms they understand
	Communicate prognosis for quantity and quality of life
	Provide anticipatory guidance regarding illness and treatment trajectories
	Develop consensus for difficult decisions in a way that is sensitive to the patient's/family's preferred role of decision-making
	Identify and manage moral distress among interdisciplinary team members
Psychosocial and spiritual support	Identify psychosocial and emotional needs of patients and families
	Identify needs for spiritual or religious support and provide referral
	Access resources that can help meet psychosocial needs
	Practice cultural humility
Goals of care	Help family establish goals of care based on patient and family values, goals, and treatment preferences
	Willing and able to engage in shared decision-making and adapt shared decision-making approach to patient and family preferences
	Incorporate ethical principles in communication and decision-making
End-of-life care	Emphasize nonabandonment and provide continued emotional support through the dying process for patients and their families
	Provide anticipatory guidance regarding the dying process for patients and their families
	Facilitate bereavement support for family members

Cruetzfeldt C, et al. Stroke. 2015;46:2714

Integrating Palliative Care

- Enhanced patient and caregiver understanding of disease, treatment, and prognosis
- Enhanced shared decision making based on patient values, preferences, and goals
- Improved patient and caregiver outcomes
- Enhanced patient-clinician communication
- Enhanced individual advance care planning based on benefits, risks, and burdens of care
- Enhanced preparation for end-of-life and associated care
- Bereavement support

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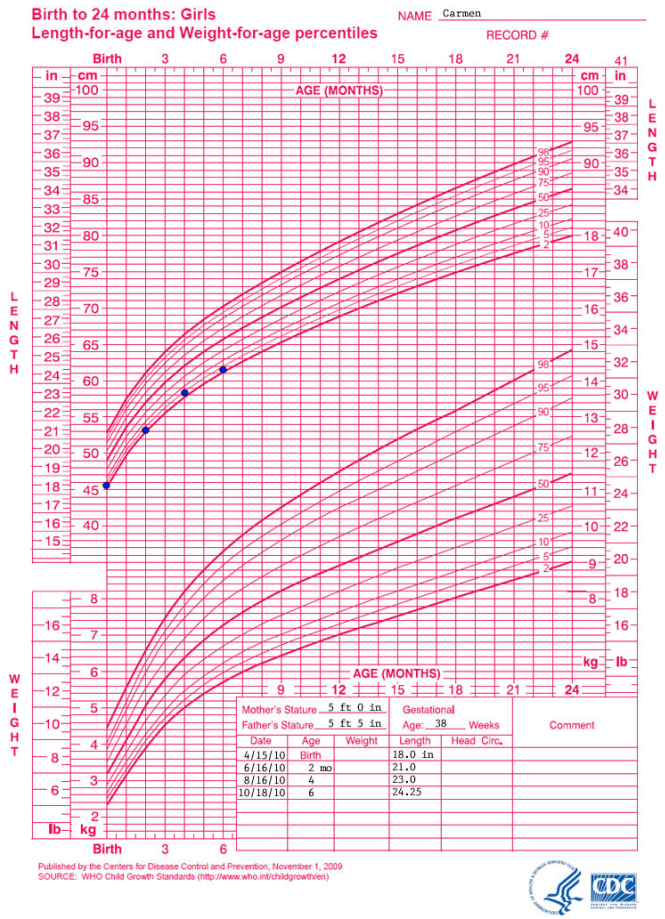
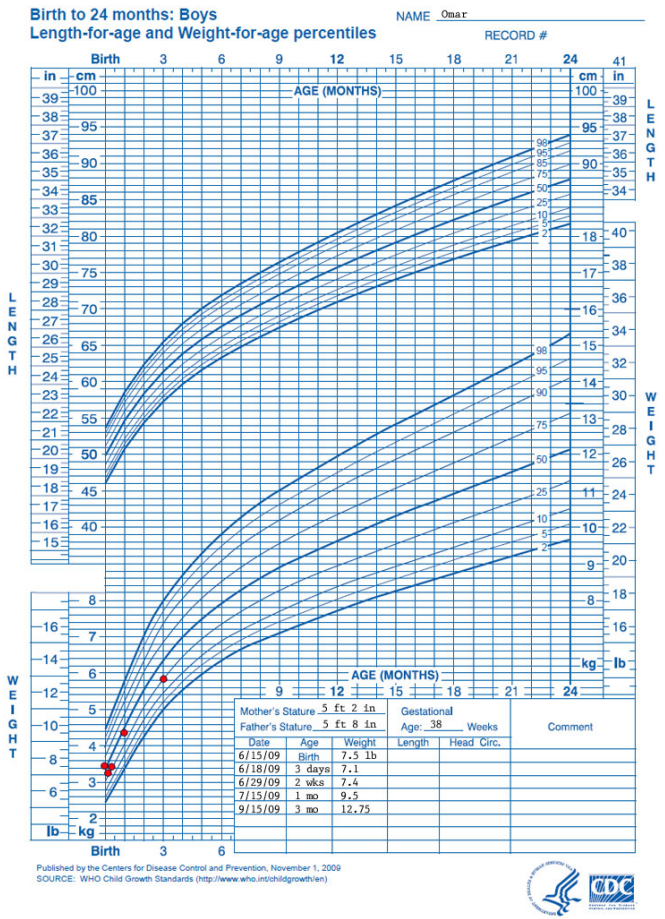
- *Illness trajectory research*
- *Evidence-based, "preference-based" decision making*
- *Incent and innovate goal-driven care*

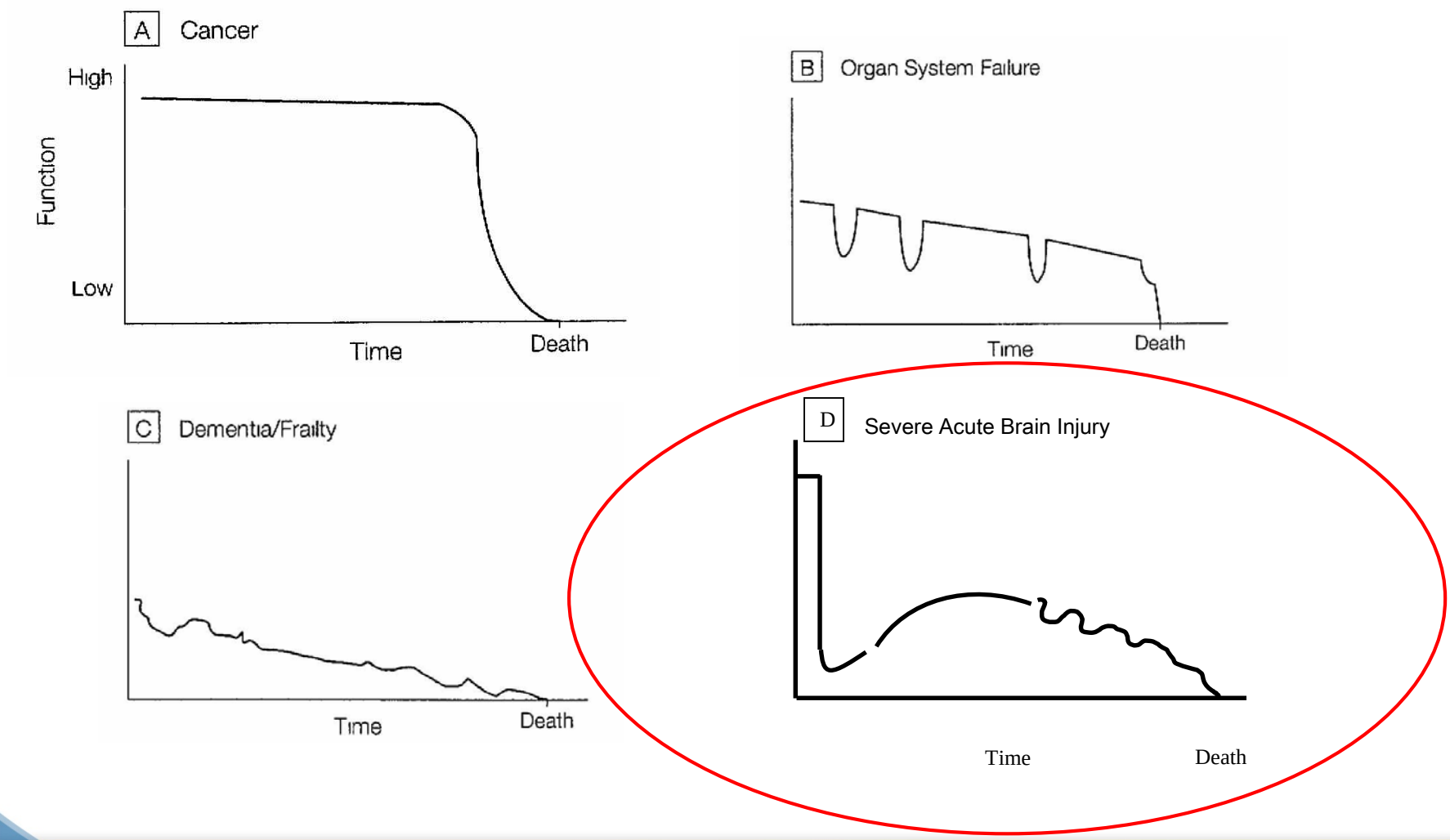
Growth Charts



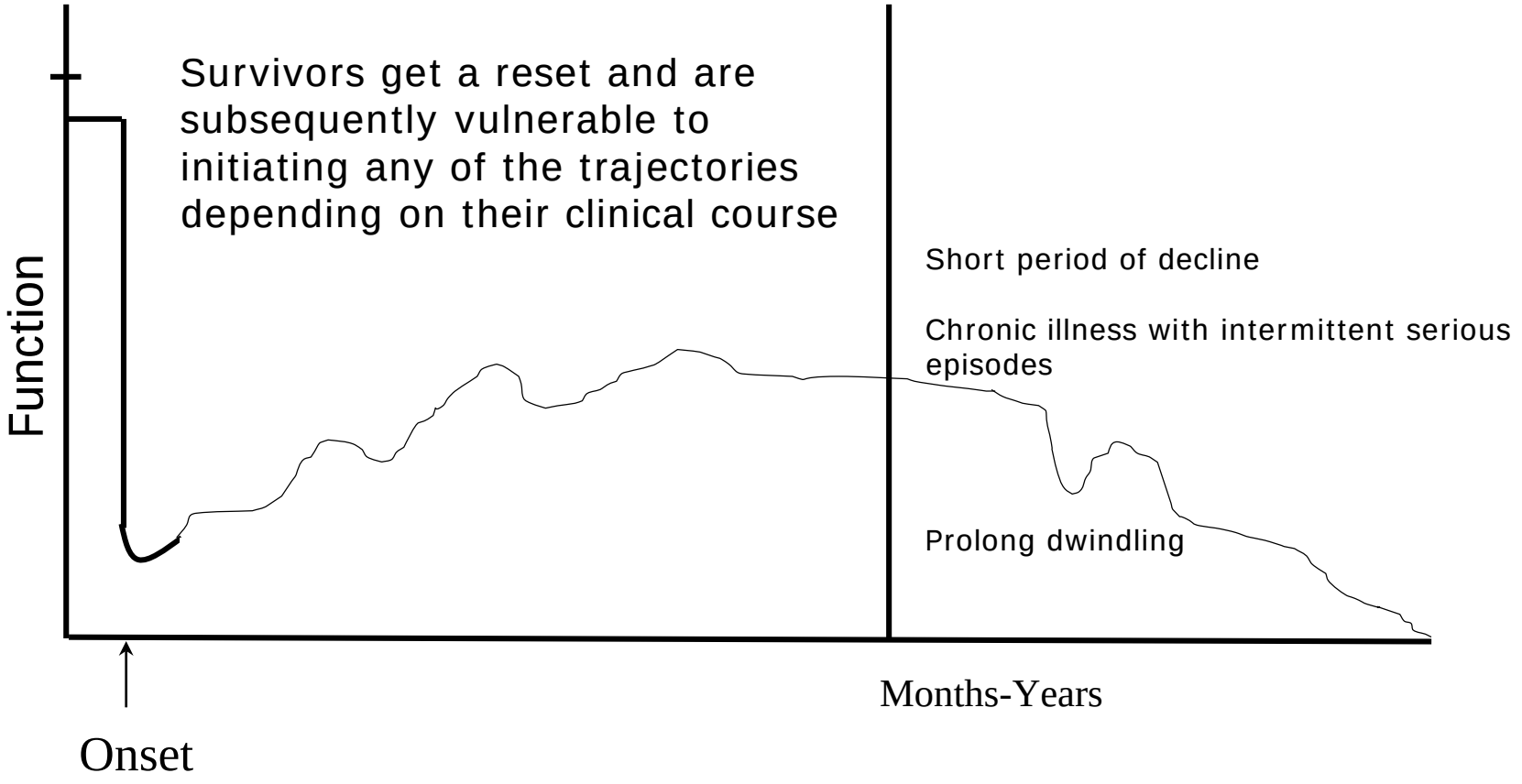


The Fourth Trajectory

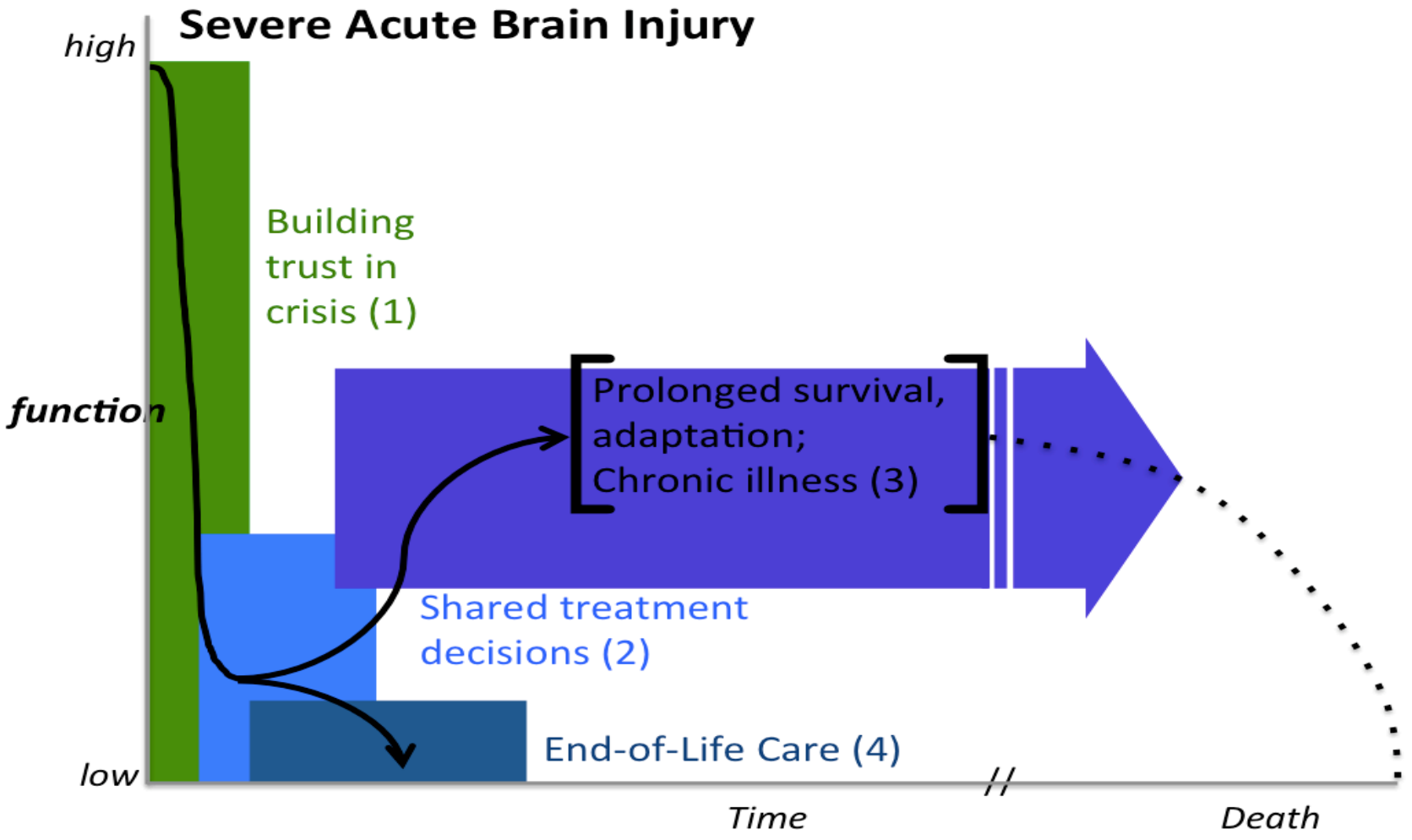
(BMJ 2015;351:h3904)



Chronic Stage “Resetting”



Severe Stroke



Implications for Health Care Systems

- Health care systems prepared for early deaths and prolonged survival
- Measuring and improving the quality of preference-based care
- Palliative care, planning and decision making, and safety during transitions.
- As we move toward creating a high-value health care system, incentives for better informed physician and patient decision-making process must be a cornerstone of this system

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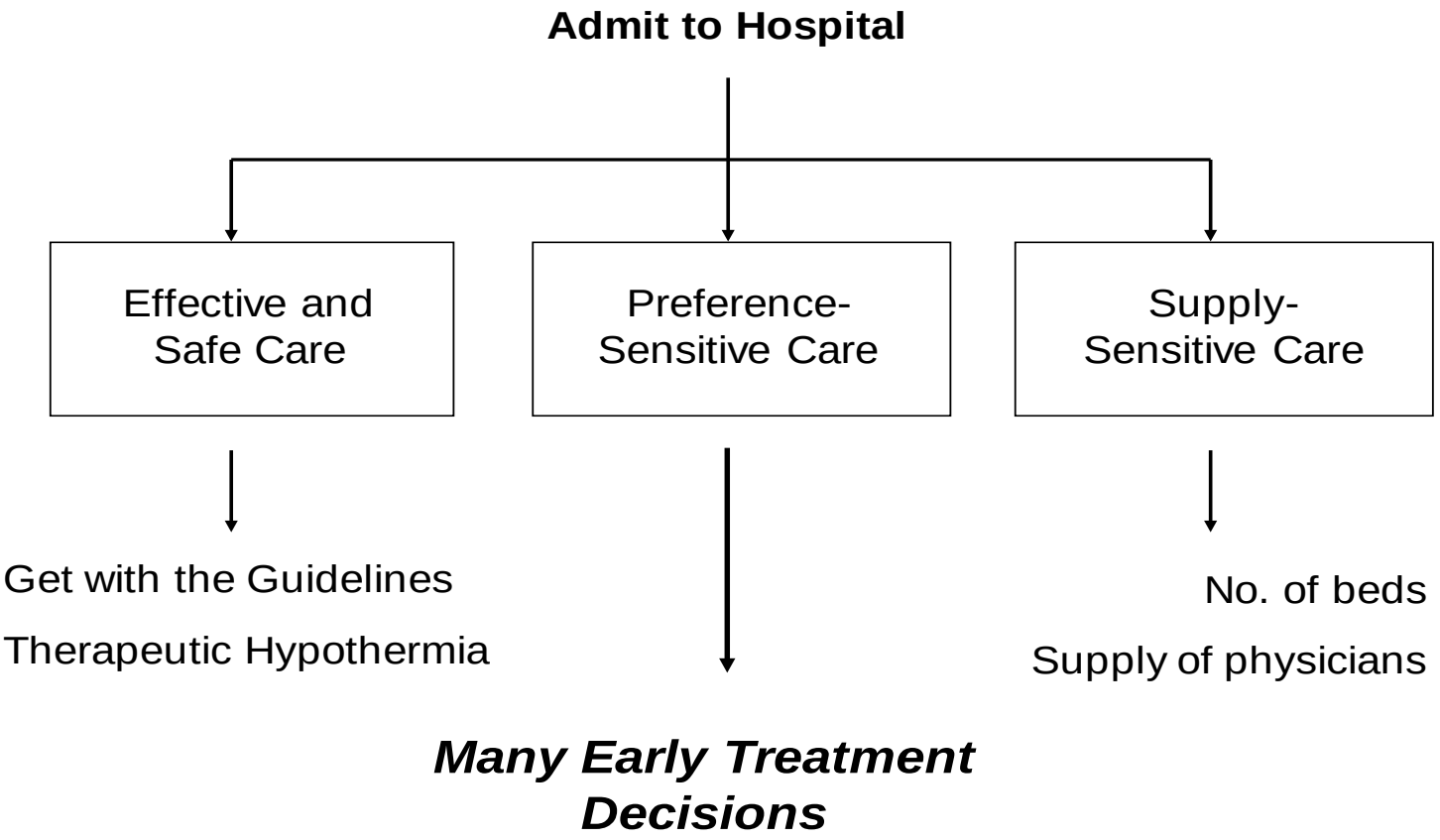
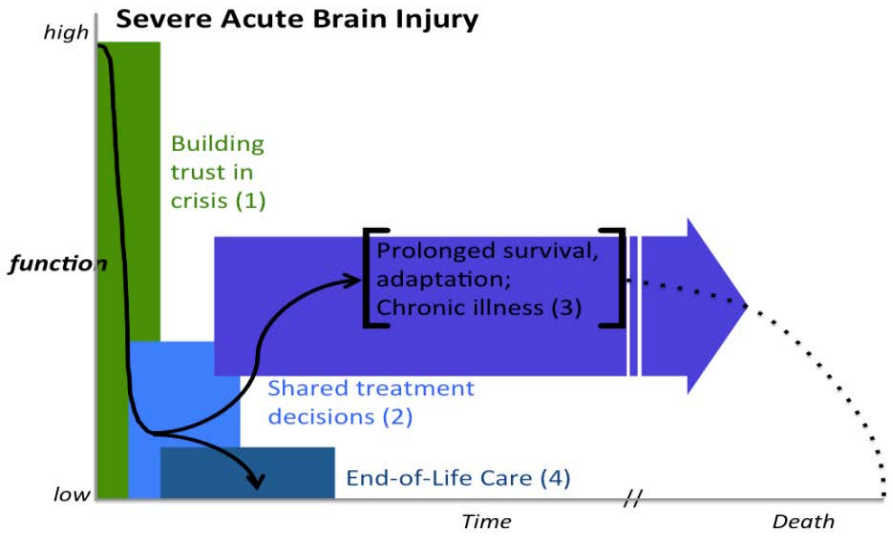


Many Early Treatment Decisions

"silent epidemic of preference misdiagnosis"

Mulley AG, BMJ, 2012

Early Treatment Decisions

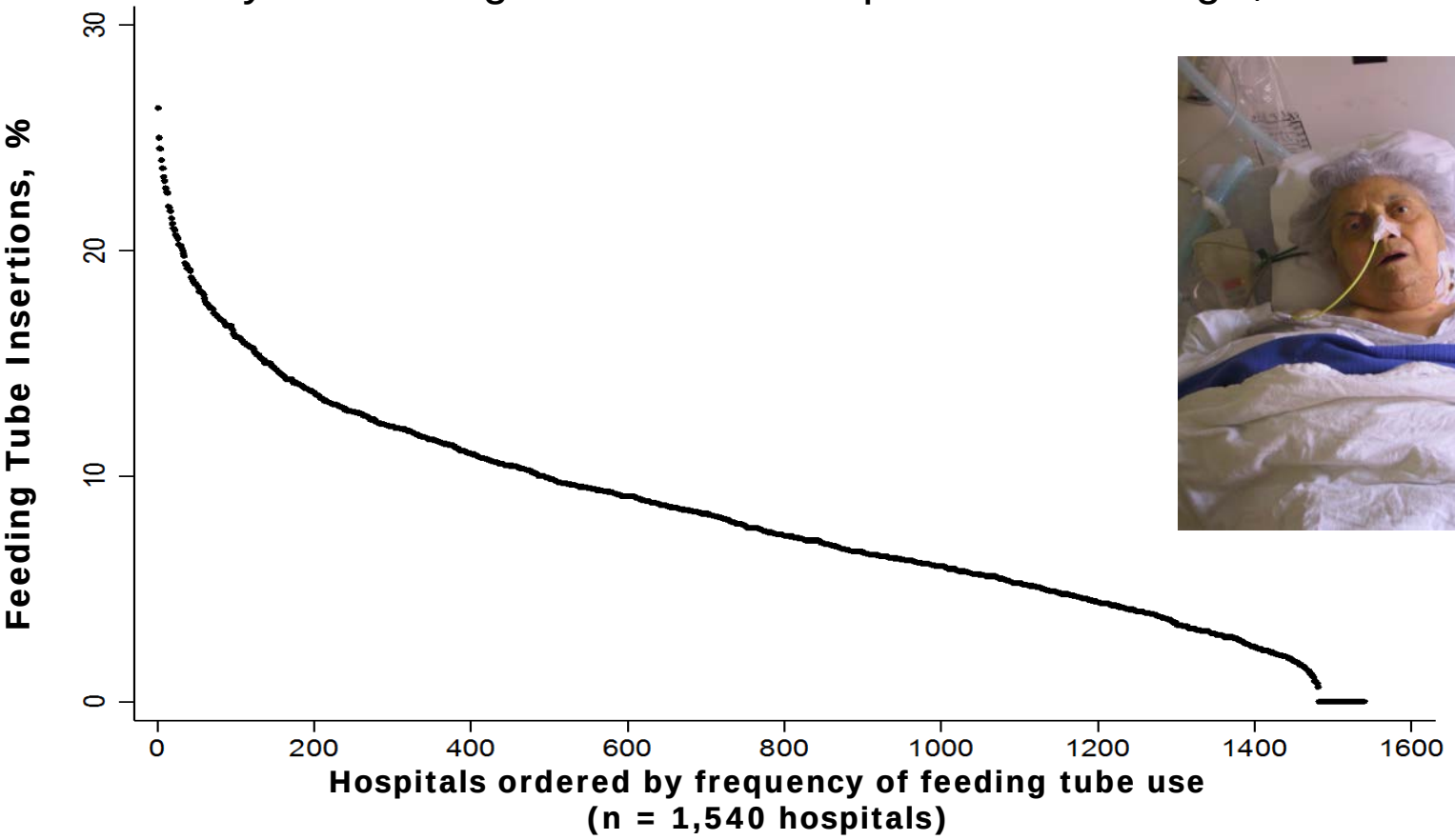


First 1-3 days	First 1-3 weeks
Thrombolytic agents	Artificial Nutrition
Intubation/Ventilation	PEG tube
Surgical Options	Tracheostomy
Advance Care Planning/DNR/DNI/Other	

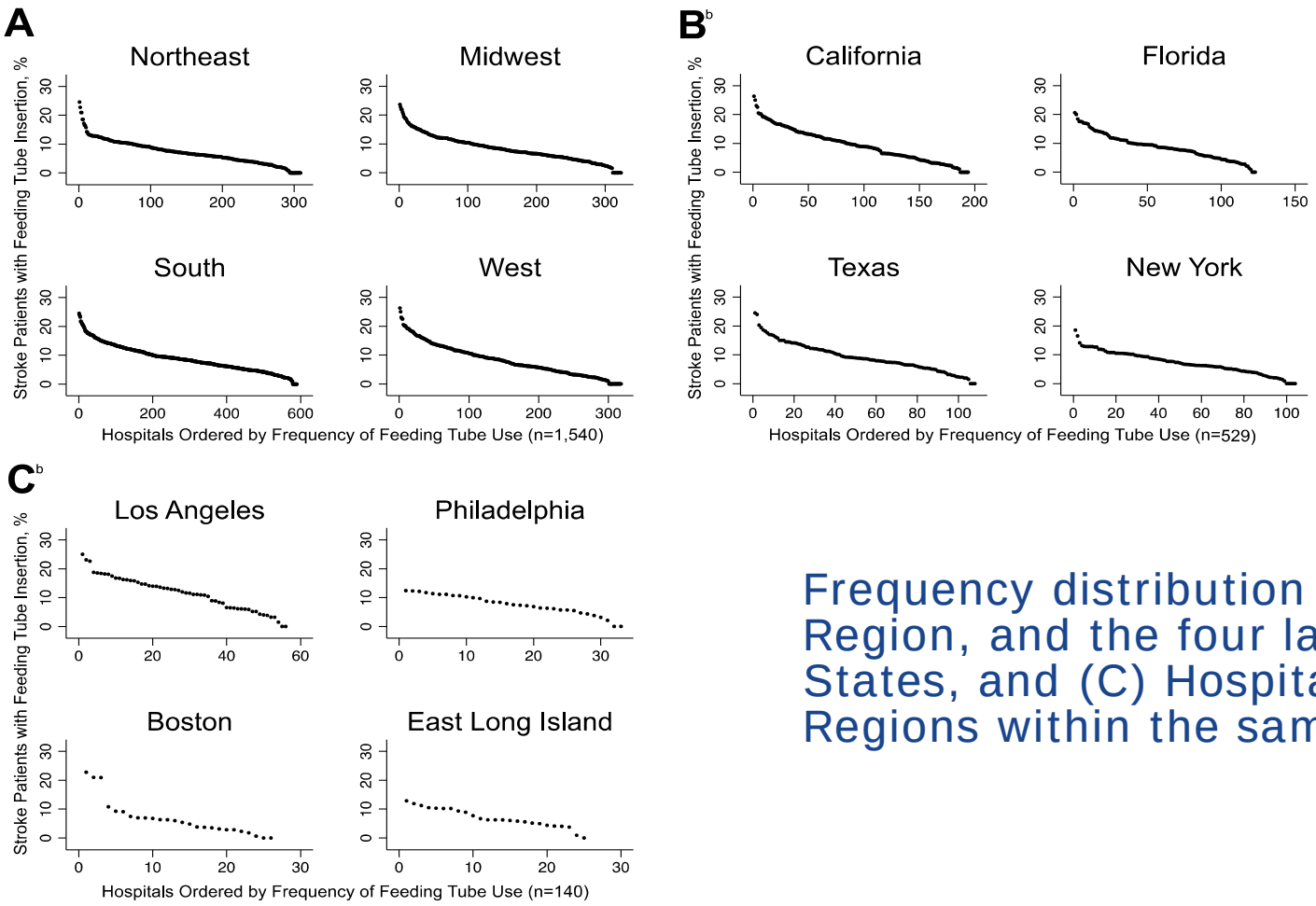
PEG after Stroke

George et al. Neurology 2014

Variability in feeding tube insertion practices is large, 2008-11



… And variation remains large within specific geographies



Frequency distribution by (A) Region, and the four largest (B) States, and (C) Hospital Referral Regions within the sample

What hospital characteristic is associated with a higher risk of being discharged with a PEG tube

A. Lower stroke volume

B. Rural location

C. For profit status

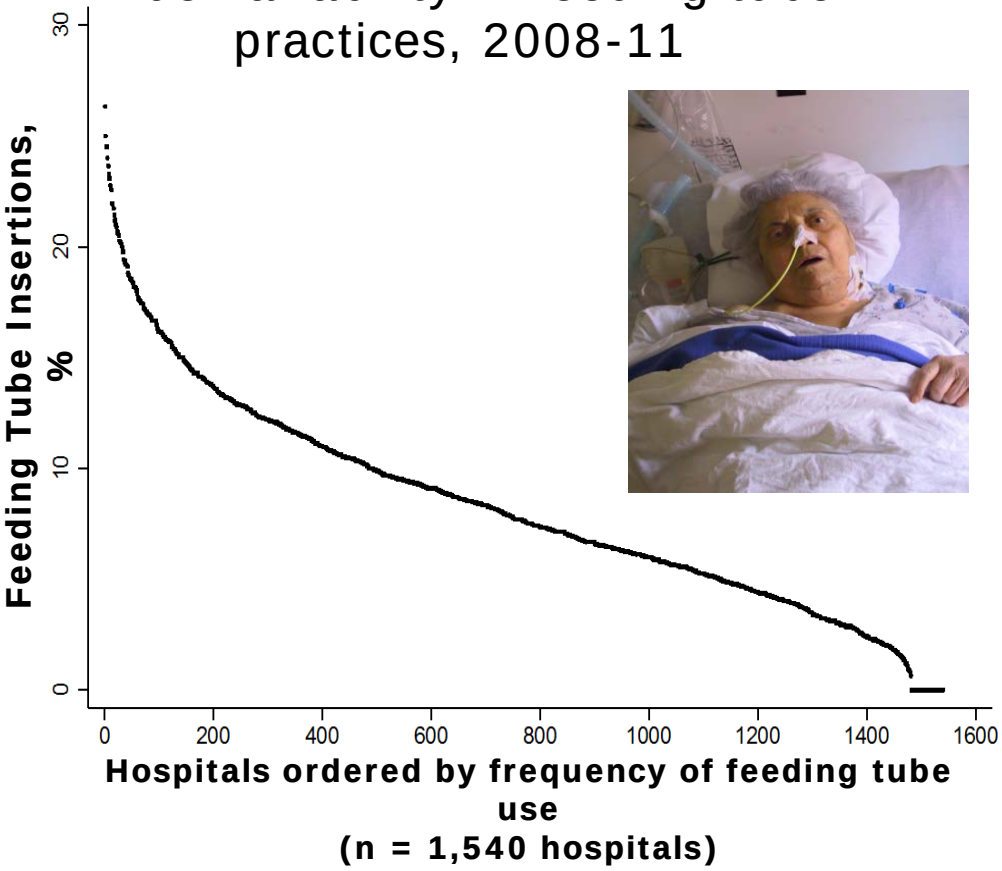
D. Lower intubation use

E. Non-teaching status

PEG after Stroke

George et al. Neurology 2014

Wide variability in feeding tube practices, 2008-11



<u>Patient factors</u> predictive of feeding tube insertion

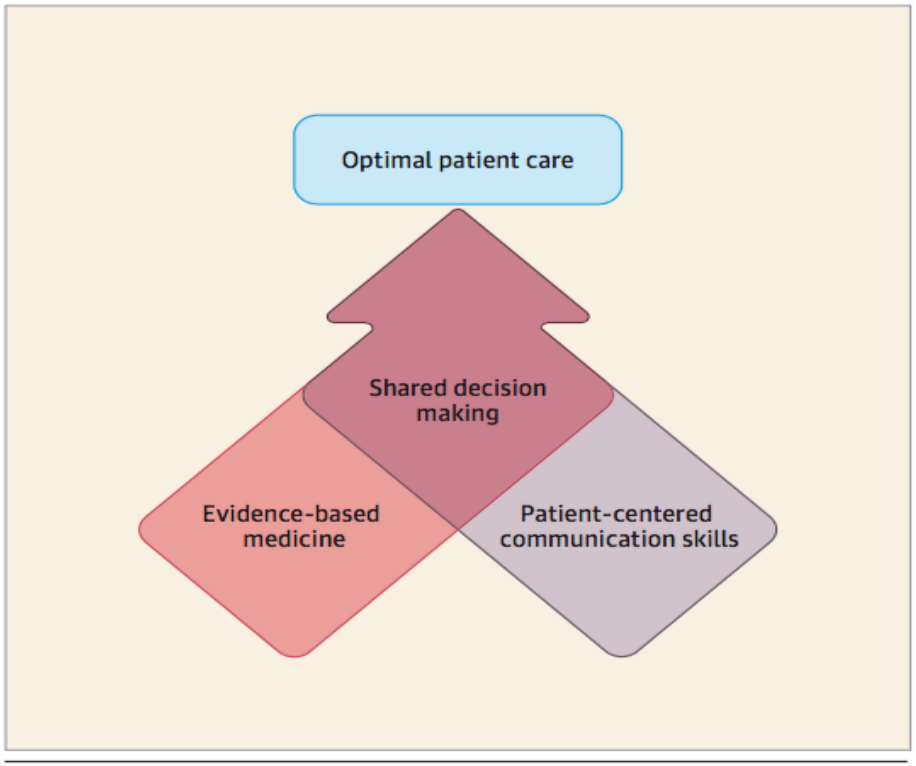
- *Age*
- *Gender*
- *Race/ethnicity*
- *Severity of comorbidity*

<u>Hospital factors</u> predictive of feeding tube insertion

- *Hospital ownership*
- *Stroke volume*
- *Intubation rate*
- *Minority admission rate*

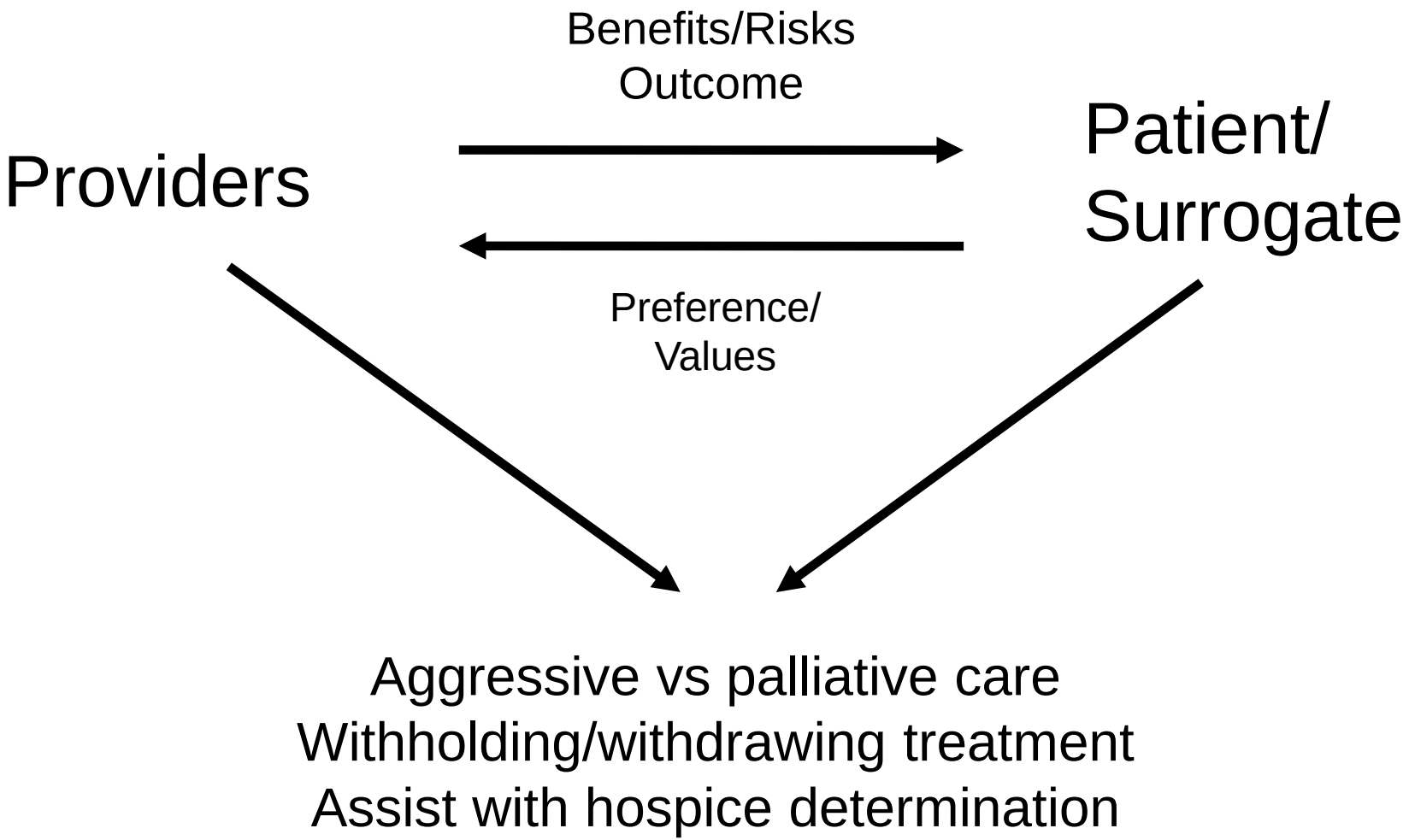
A Model of Optimal Care

Figure. The Interdependence of Evidence-Based Medicine and Shared Decision Making and the Need for Both as Part of Optimal Care

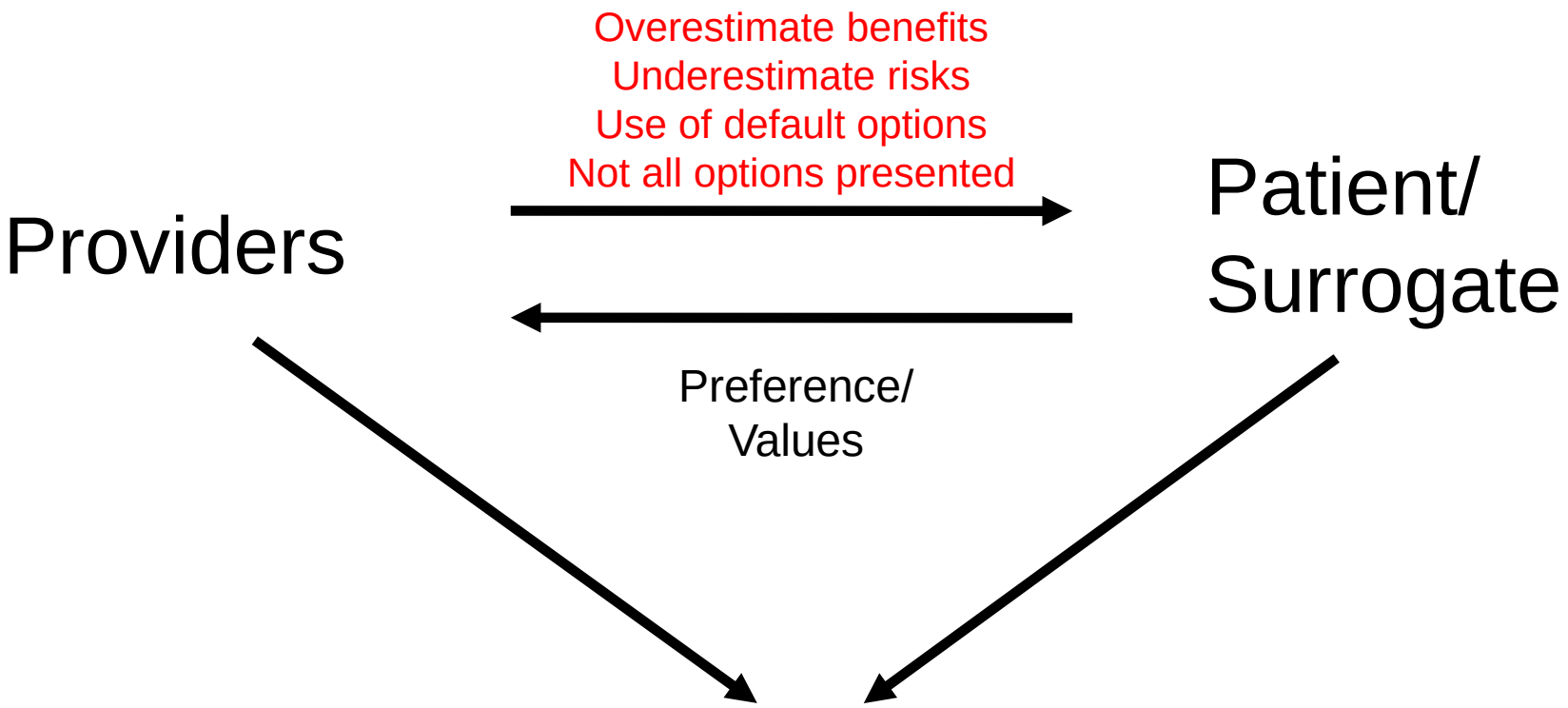


Hoffmann, Montori, Del Mar. "The connection between evidence-based medicine and shared decision making." *JAMA* 312.13 (2014): 1295-1296.

Shared-Decision Making



Shared-Decision Making



Aggressive vs palliative care
Withholding/withdrawing treatment
Assist with hospice determination

Are treatment preferences of stroke patients who die ever heard?

Objective: To quantify the extent of documentation of preferences for life-sustaining interventions (LSI) in a population-based cohort of ischemic stroke patients who died within 30 days post-stroke in California.

Design/Methods: We used the California Office of Statewide Health Planning Patient Discharge Database to identify all adults with ischemic strokes at all California acute care hospitals from December 2006 to November 2007.

Results/Conclusion: Among a representative sample of California patients who died within 30 days after an ischemic stroke, less than half (93/198, 47%) had documented discussions about life sustaining interventions.

Maisha Robinson 2015, work in progress

What percent of surrogates rely exclusively on physicians as a source of prognostic information?

A. 2%

B. 10%

C. 25%

D. 40%

E. 60%

F. 80%

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A. 2%

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D. 40%

E. 60%

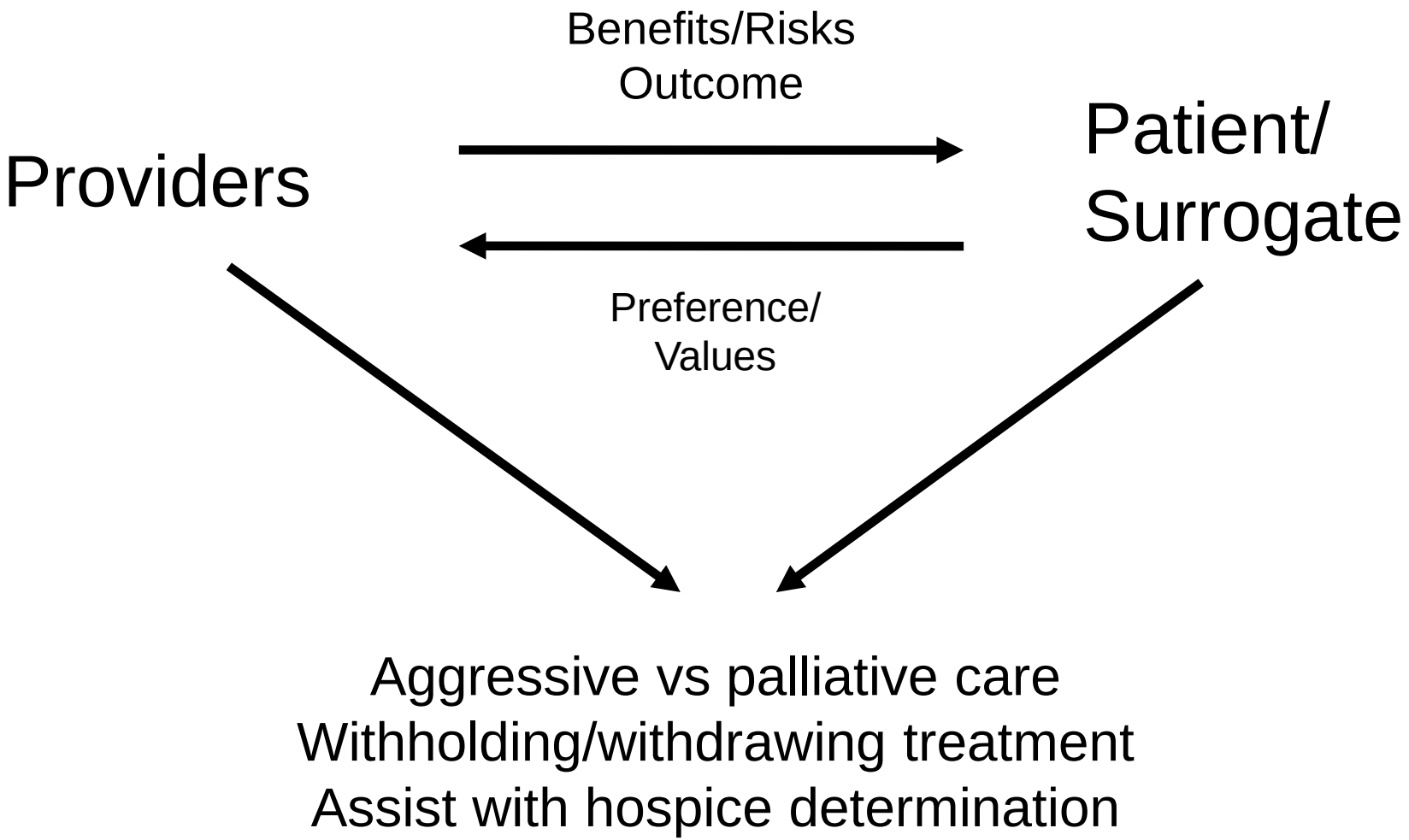
F. 80%

Crit Care Med. 2010;38:1270-75

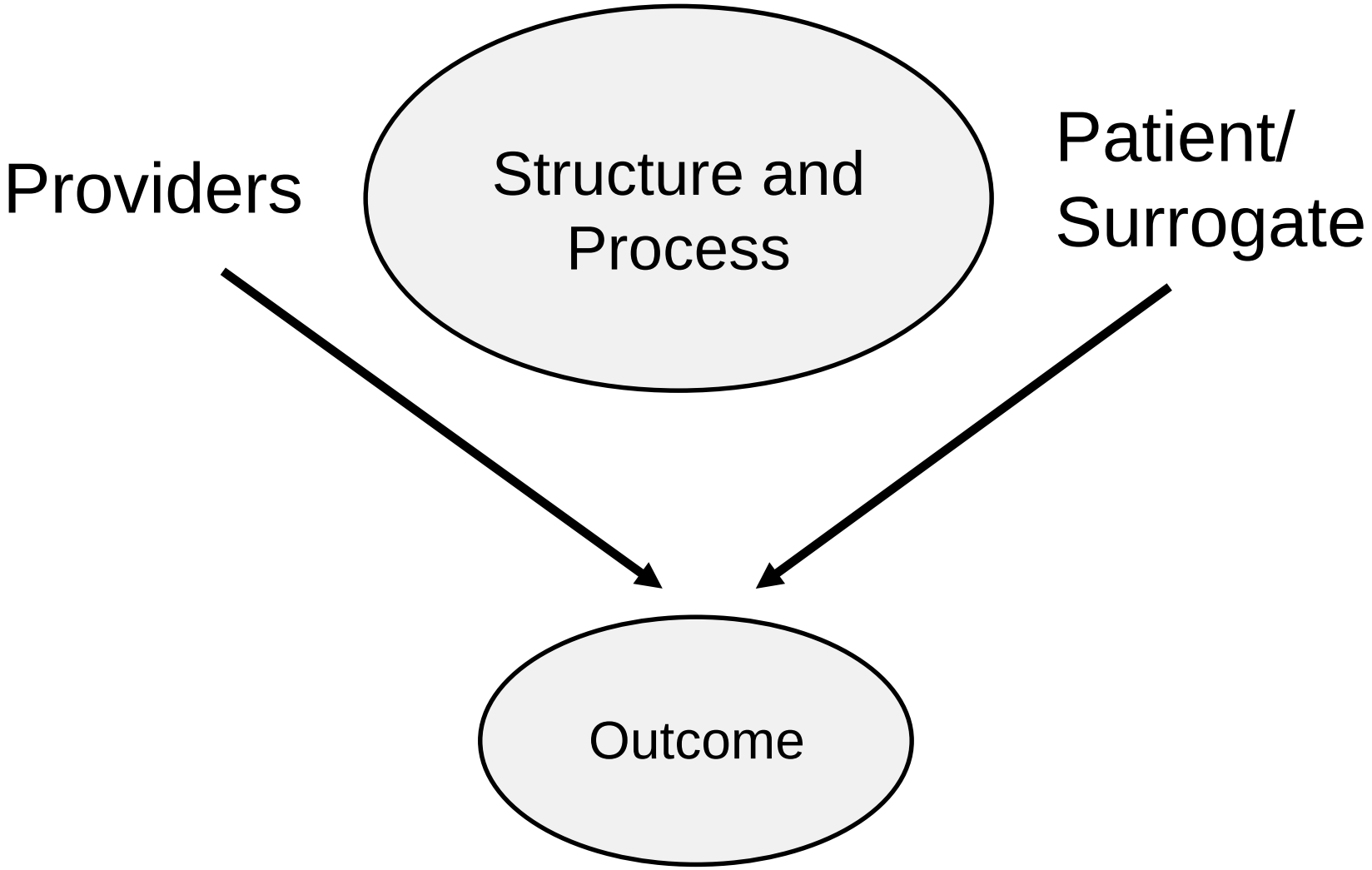
The majority of surrogates cited other factors including:

1. Perceptions of the patients strength of character and will to live
2. Patient's unique history of illness and survival
3. Surrogate's observations of the patient's physical appearance
4. Surrogate's belief that their bedside presence improves prognosis
5. Surrogate's own optimism, intuition and faith

Shared-Decision Making



Shared-Decision Making



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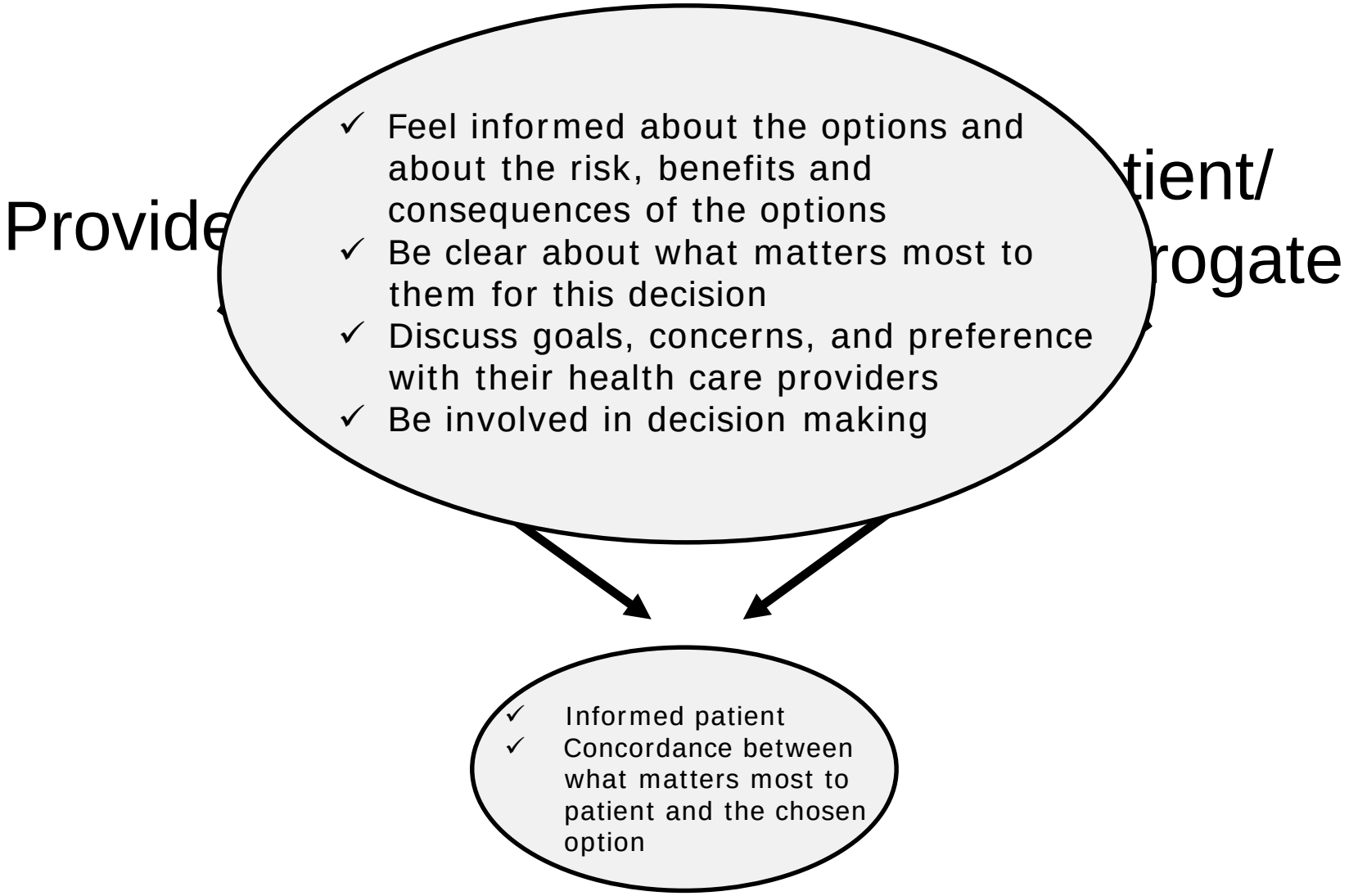

Decision Aids in Serious Illness
Moving what works into practice

- 17 RCTs: 6 for advance care planning and 11 for current treatment options
- Decision aids are acceptable and feasible and can modify patients' expressed preferences.
- Increase ease of decision making reduce decisional conflict and modify the decisions made.
- No study answered the most important question – are patients who complete such interventions more likely to receive the care that they actually prefer?

JAMA Intern Med 175; 2015:1213

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The Right Incentives?

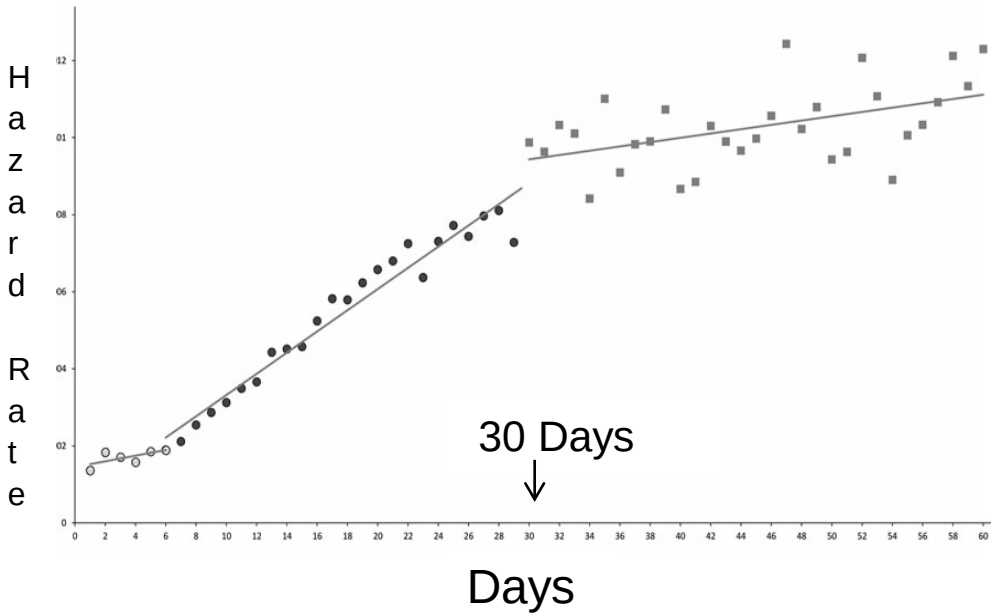
CMS began publicly reporting 30-day risk standardized stroke mortality in **December 2014**

Mary Rowan

Died May 29, 2010

"….In lieu of flowers, contributions may be made to the Sussman Palliative Care Unit at Strong Memorial Hospital…"

Temporal changes in survival after cardiac surgery are associated with the thirty-day mortality benchmark



Health Services Research 49:5 (October 2014): 1659

An Evolving Measurement Framework

Existing Measures

Dysphagia screen

Time to thrombolytics – 60

IV rt-PA by 3.5, treat by 4.5

VTE prophylaxis

Antithrombotics

Anticoag for afib/flutter

NIHSS reported

Stroke education

Rehab considered

LDL documented

Statin

Palliative Care v2

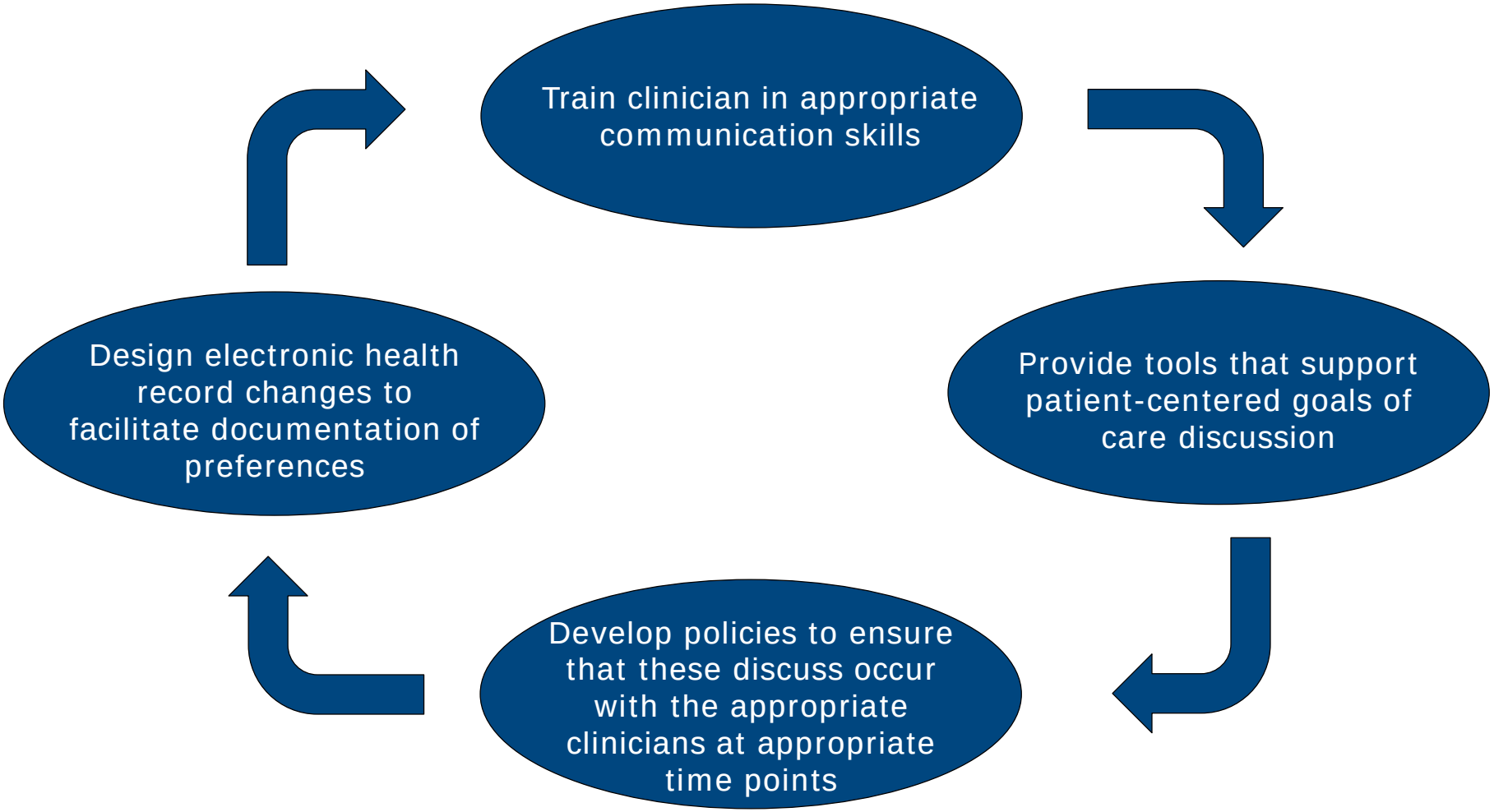
Priorities/values documented

Timing of goals of care discussion

Informed about decision

Level of conflict/agreement

The QI Approach



Summary
(AHA/ASA Palliative Care Policy Recommendations, forthcoming)

- Provide patients with access to continuous, coordinated, comprehensive, high-quality palliative care provided *concurrently* with specialist-level stroke care;
- Promote well-prepared, empowered individuals and families;
- Customize care to reflect patient and family preferences, as well as the unique situation of each individual;
- Develop and support a skilled, compassionate and responsive healthcare workforce;
- Embed and actualize continual structure and performance assessment based on these principles.

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