IRE
ISTITUTO NAZIONALE TUMORI
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ISTITUTO DI RICOVERO E CURA A CARATTERE SCIENTIFICO

End of life decison making for neurological patients

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WCN
2015

Conflict of Interest

Pace, Andrea

- No conflict of interest to declare

Learning Objectives

- To understand PC needs at the end of life
- To recognize EoL issues in neurological diseases
- To improve knowledge about EoL decision-making-process in neurology
- To be able to manage the most common EoL symptoms and problems

Neurology 1999;53:284

End-of-life care

A survey of US neurologists' attitudes, behavior, and knowledge

A.C. Carver, MD; B.G. Vickrey, MD, MPH; J.L. Bernat, MD; C. Keran;
S.P. Ringel, MD; and K.M. Foley, MD

- 353 neurologists
- 152 neuro-oncologists
- ALS specialists

"..evident lack of knowledge of the law, and confusion, disagreement or both concerning medical and ethical guidelines.."

"..there is a great need for education in palliative care and end-of-life decision-making.."

Palliative care and neurology

Time for a paradigm shift

Neurology® 2014;83:561-567

DO NEUROLOGY PATIENTS HAVE UNIQUE PALLIATIVE CARE NEEDS?

Patients with a life-limiting neurologic illness often have a long and variable disease progression punctuated by cognitive impairment, behavioral issues, and communication problems, in addition to motor symptoms

WHAT PALLIATIVE CARE SKILLS NEUROLOGISTS NEED?

All neurologists, should have familiarity and comfort with several fundamental palliative care skills including communicating bad news, nonmotor symptom assessment and management, advance care planning, and caregiver assessment.

Palliative care and neurology

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Neurology® 2014;83:561-567

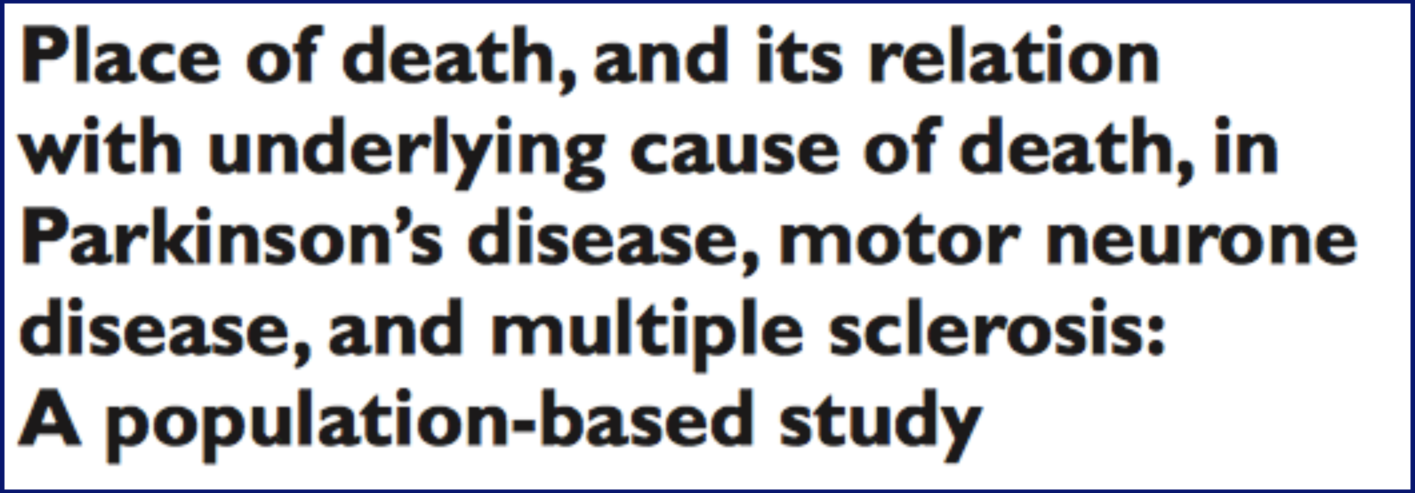
SYMPTOM ASSESSMENT AND MANAGEMENT

Neurologists need to carefully assess nonmotor symptoms such as pain, depression, anxiety, fatigue, sleep, constipation, urinary urgency, and sexual dysfunction.

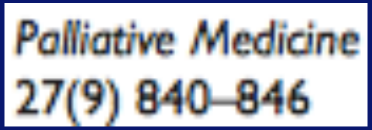
Multiple studies have shown that nonmotor symptoms over time are among the most function-limiting for patients, and affect caregiver burden and overall quality of life more than motor symptoms.

ADVANCE CARE PLANNING

All neurologists should be knowledgeable about and feel comfortable discussing advance care planning with their patients while the patient is cognitively able.



Place of death, and its relation with underlying cause of death, in Parkinson’s disease, motor neurone disease, and multiple sclerosis: A population-based study



Palliative Medicine
27(9) 840–846

Home deaths MND (27.1%) MS (18.4%) and PD (9.7%)

Hospital deaths MND (45.1%) MS (55.8%) and PD (43.4%)

Hospice deaths MND (11.2%) MS (2.5%) and PD (0.6%)

Specific symptoms in neurological diseases

	MOTOR	PAIN	INFECTION	DYSPNOEA	EPILEPSY	DYSPHAGIA	COGN
Stroke	●	●		●	●	√	●
MS	●	●	●	●		●	
PD	●	●		●		●	●
DEM	•	●	●	●	●	●	●
MND	●	●		●		●	
BT	●	•		●	●	●	●

MS=Multiple Sclerosis ;PD= Parkinson Disease; DEM= Dementia; MND=Motor Neuron Disease; BT= Brain Tumor

Neurologic Disease at the End of Life: Caregiver Descriptions of Parkinson Disease and Amyotrophic Lateral Sclerosis

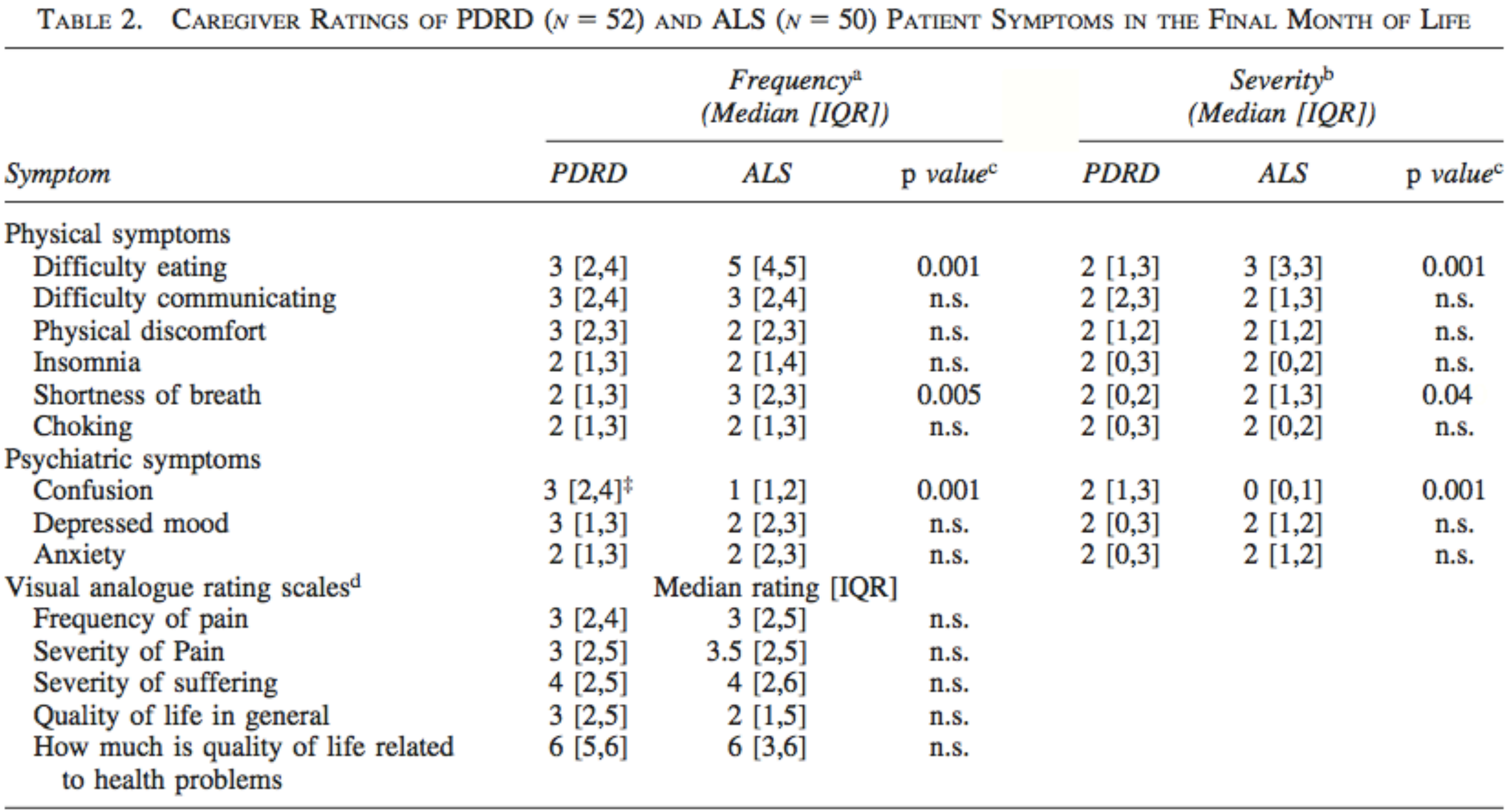


TABLE 2. CAREGIVER RATINGS OF PDRD ($N = 52$) AND ALS ($N = 50$) PATIENT SYMPTOMS IN THE FINAL MONTH OF LIFE

	Frequency[a] *(Median [IQR])*			*Severity*[b] *(Median [IQR])*		
Symptom	*PDRD*	*ALS*	p *value*[c]	*PDRD*	*ALS*	p *value*[c]
Physical symptoms						
Difficulty eating	3 [2,4]	5 [4,5]	0.001	2 [1,3]	3 [3,3]	0.001
Difficulty communicating	3 [2,4]	3 [2,4]	n.s.	2 [2,3]	2 [1,3]	n.s.
Physical discomfort	3 [2,3]	2 [2,3]	n.s.	2 [1,2]	2 [1,2]	n.s.
Insomnia	2 [1,3]	2 [1,4]	n.s.	2 [0,3]	2 [0,2]	n.s.
Shortness of breath	2 [1,3]	3 [2,3]	0.005	2 [0,2]	2 [1,3]	0.04
Choking	2 [1,3]	2 [1,3]	n.s.	2 [0,3]	2 [0,2]	n.s.
Psychiatric symptoms						
Confusion	3 [2,4][‡]	1 [1,2]	0.001	2 [1,3]	0 [0,1]	0.001
Depressed mood	3 [1,3]	2 [2,3]	n.s.	2 [0,3]	2 [1,2]	n.s.
Anxiety	2 [1,3]	2 [2,3]	n.s.	2 [0,3]	2 [1,2]	n.s.
Visual analogue rating scales[d]	Median rating [IQR]					
Frequency of pain	3 [2,4]	3 [2,5]	n.s.			
Severity of Pain	3 [2,5]	3.5 [2,5]	n.s.			
Severity of suffering	4 [2,5]	4 [2,6]	n.s.			
Quality of life in general	3 [2,5]	2 [1,5]	n.s.			
How much is quality of life related to health problems	6 [5,6]	6 [3,6]	n.s.			

JOURNAL OF PALLIATIVE MEDICINE
Volume 11, Number 4, 2008

Signs of approaching death

Triggers for End of Life care

- Changes in breathing
- General deterioration
- Lowering of consciousness
- Lowered oral intake
- Repeated infections
- Weight loss
- Caregivers’ judgment

Palliative Care in Amyotrophic Lateral Sclerosis, Parkinson's Disease, and Multiple Sclerosis

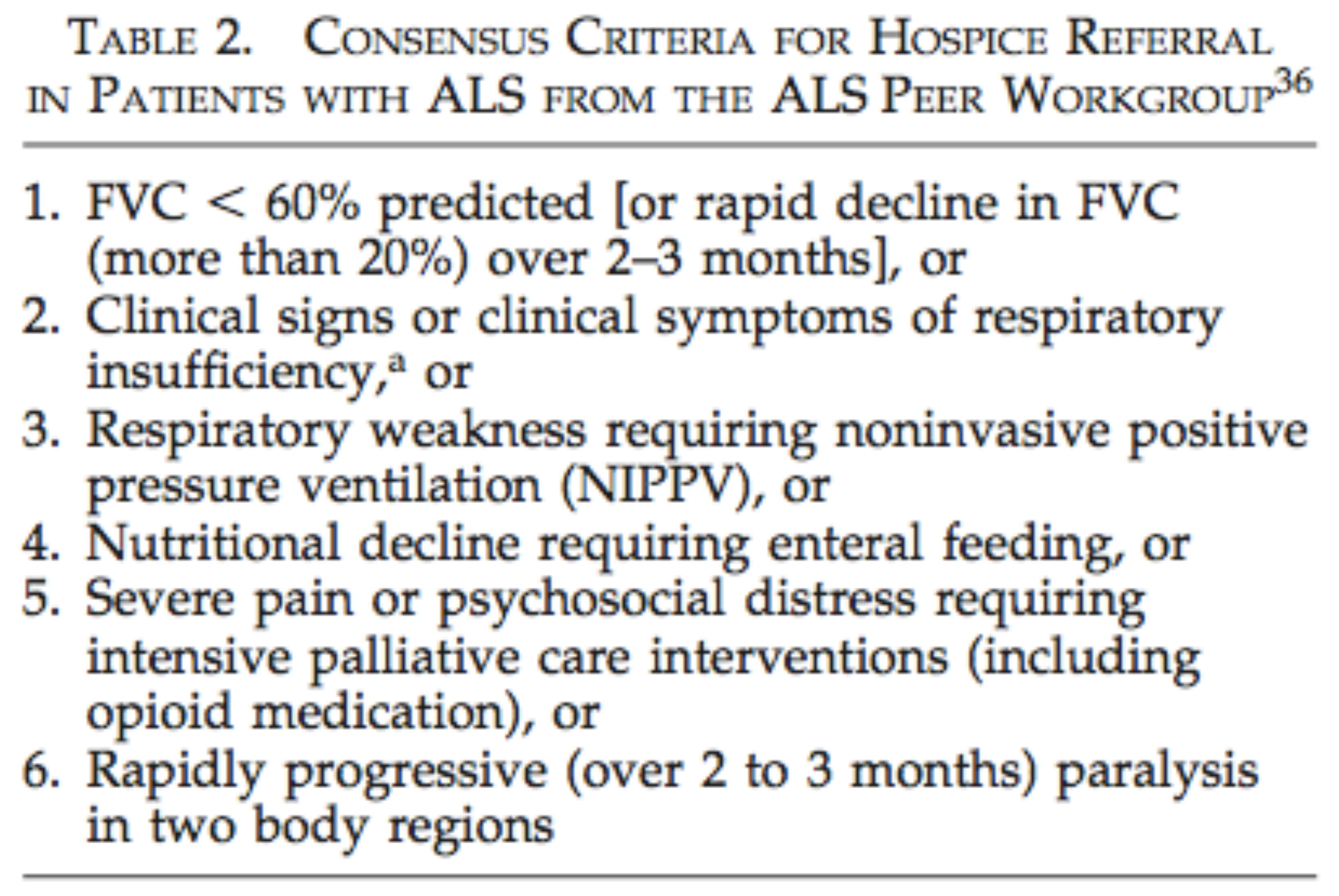


Table 2. Consensus Criteria for Hospice Referral in Patients with ALS from the ALS Peer Workgroup[36]

1. FVC < 60% predicted [or rapid decline in FVC (more than 20%) over 2–3 months], or
2. Clinical signs or clinical symptoms of respiratory insufficiency,[a] or
3. Respiratory weakness requiring noninvasive positive pressure ventilation (NIPPV), or
4. Nutritional decline requiring enteral feeding, or
5. Severe pain or psychosocial distress requiring intensive palliative care interventions (including opioid medication), or
6. Rapidly progressive (over 2 to 3 months) paralysis in two body regions

JOURNAL OF PALLIATIVE MEDICINE
Volume 10, Number 2, 2007

Dysphagia as a predictor of outcome and transition to palliative care among middle cerebral artery ischemic stroke patients

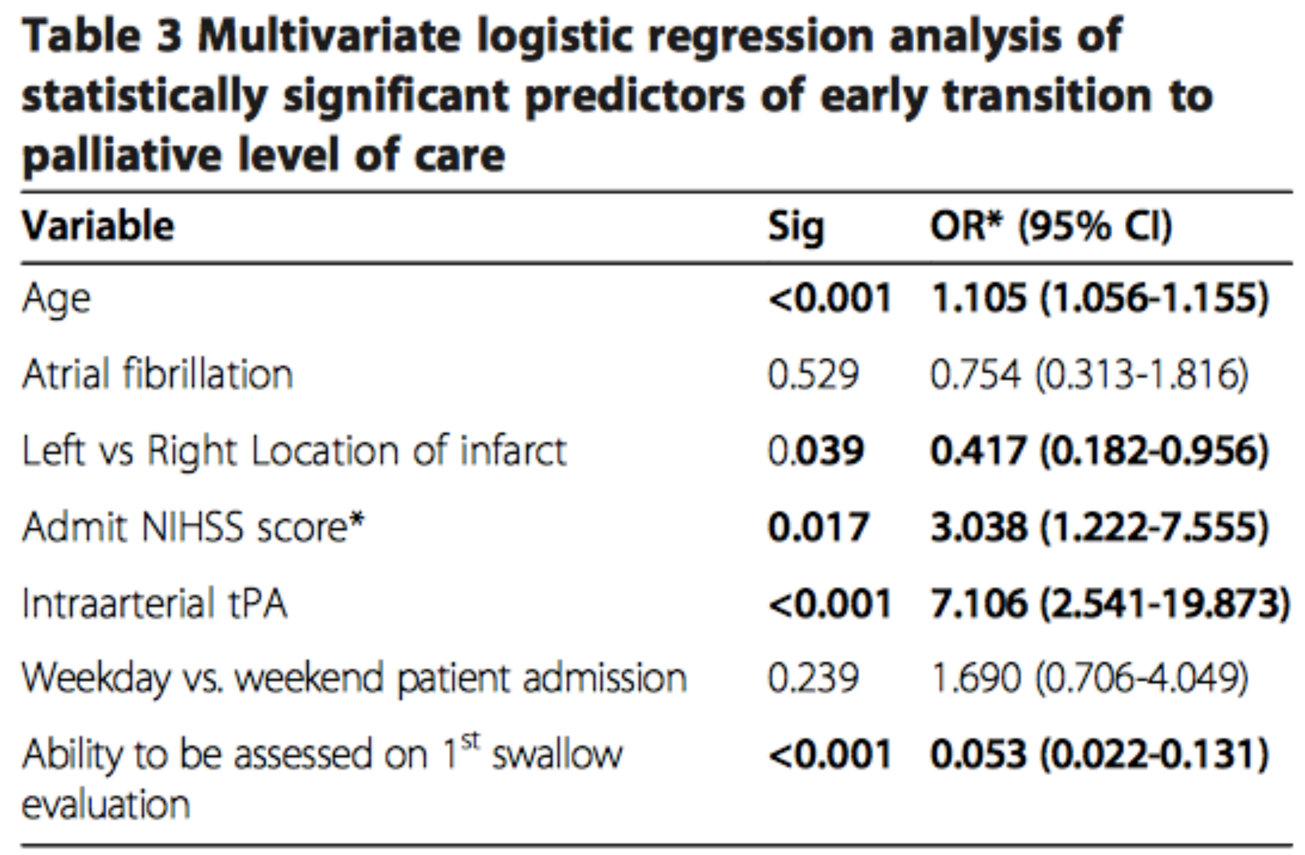


Table 3 Multivariate logistic regression analysis of statistically significant predictors of early transition to palliative level of care

Variable	Sig	OR* (95% CI)
Age	**<0.001**	**1.105 (1.056-1.155)**
Atrial fibrillation	0.529	0.754 (0.313-1.816)
Left vs Right Location of infarct	0.**039**	**0.417 (0.182-0.956)**
Admit NIHSS score*	**0.017**	**3.038 (1.222-7.555)**
Intraarterial tPA	**<0.001**	**7.106 (2.541-19.873)**
Weekday vs. weekend patient admission	0.239	1.690 (0.706-4.049)
Ability to be assessed on 1st swallow evaluation	**<0.001**	**0.053 (0.022-0.131)**

Dysphagia severity and the inability to be assessed on the first swallow evaluation due to lethargy, influence early transition to palliative level of care among patients with acute MCA territory stroke.

San Luis *et al. BMC Palliative Care* 2013, **12**:21

End of Life decisions

- Withdrawing/withholding medical treatment
- Symptom management
- Place of death
- Information and communication
- Futility of treatment
- How to address patients’ wishes
- How to address relatives’ wishes

Palliative care needs of patients with neurologic or neurosurgical conditions

L. M. Chahine[a], B. Malik[a] and M. Davis[b]

European Journal of Neurology 2008, **15:** 1265–1272

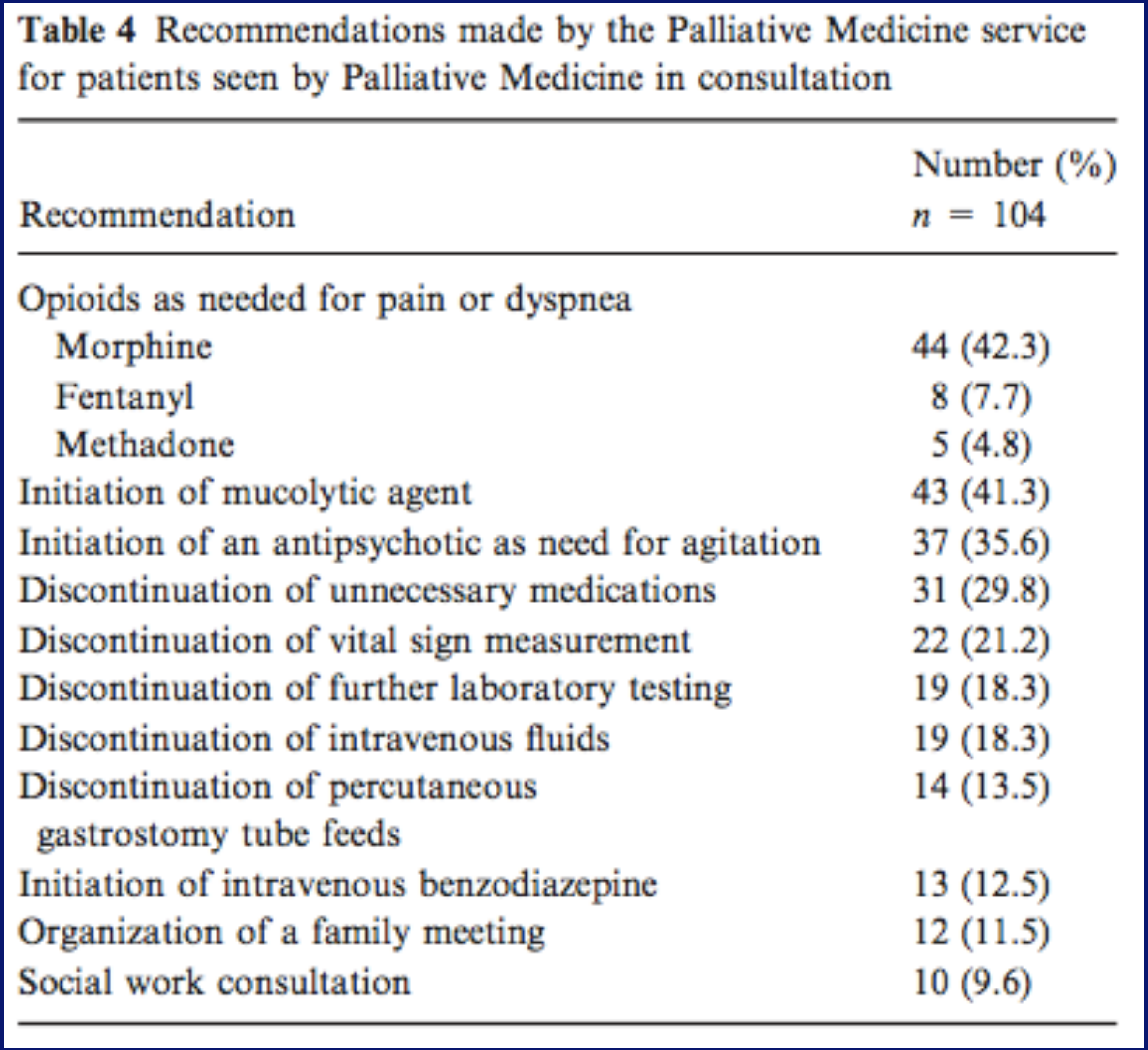


Table 4 Recommendations made by the Palliative Medicine service for patients seen by Palliative Medicine in consultation

Recommendation	Number (%) $n = 104$
Opioids as needed for pain or dyspnea	
Morphine	44 (42.3)
Fentanyl	8 (7.7)
Methadone	5 (4.8)
Initiation of mucolytic agent	43 (41.3)
Initiation of an antipsychotic as need for agitation	37 (35.6)
Discontinuation of unnecessary medications	31 (29.8)
Discontinuation of vital sign measurement	22 (21.2)
Discontinuation of further laboratory testing	19 (18.3)
Discontinuation of intravenous fluids	19 (18.3)
Discontinuation of percutaneous gastrostomy tube feeds	14 (13.5)
Initiation of intravenous benzodiazepine	13 (12.5)
Organization of a family meeting	12 (11.5)
Social work consultation	10 (9.6)

Nutrition – Hydration

Ethical challenges:

- Are nutrition and hydration medical treatments?
- Suspending food and water may shorten patient life?
- Prolonging life with artificial nutrition is beneficial for patients dying?

The principle of proportionality:

If a dying patient receiving nutrition and hydration suffers burdens that outweigh the benefit of extended life, artificial nutrition and hydration may be ethically withheld or withdrawn.

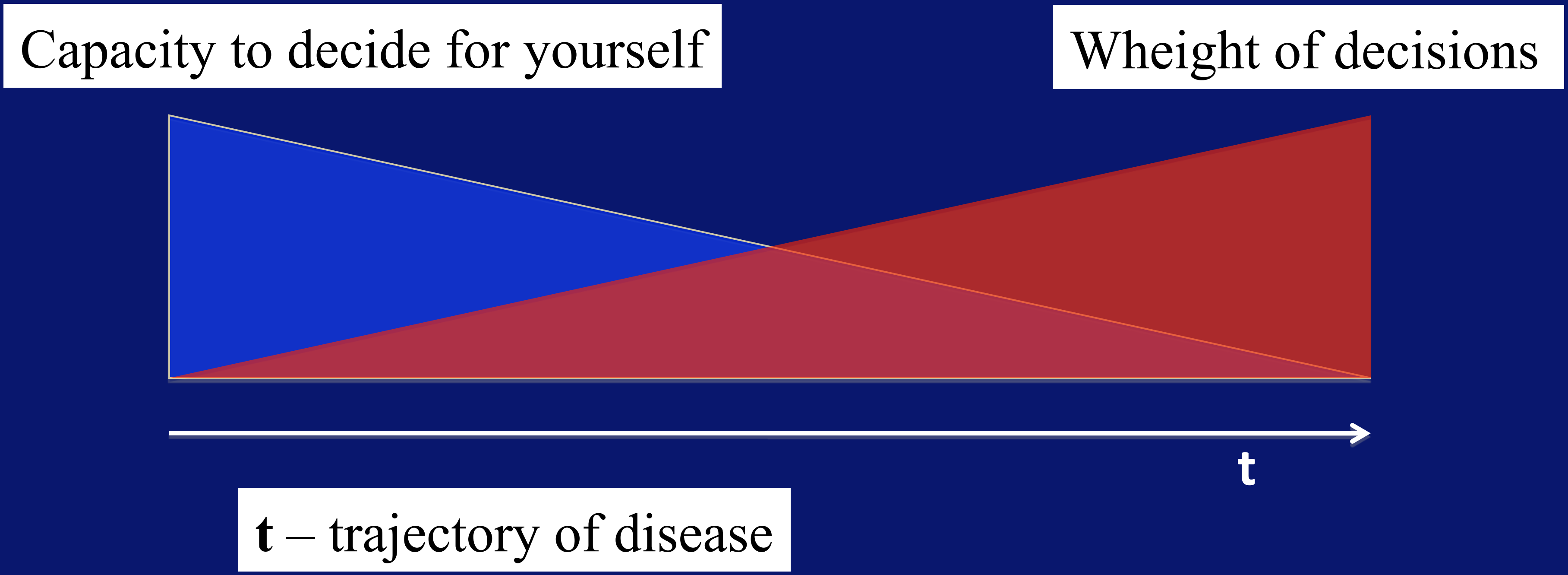
Palliative sedation

Definition: intentional reduction of vigilance up to the point of the complete loss of consciousness with the aim of reducing or abolishing the perception of symptoms that would otherwise be intolerable (“refractory”)

Aim: The aim of sedation is, like everything else in palliative care, the relief of symptoms and not the shortening of life

Is palliative sedation a “slow euthanasia”?
Several studies indicate that there is no difference in the survival of sedated and non-sedated patients
(Maltoni, Current Opinion in Oncology 2013)

Ethical relevance of patients' competence



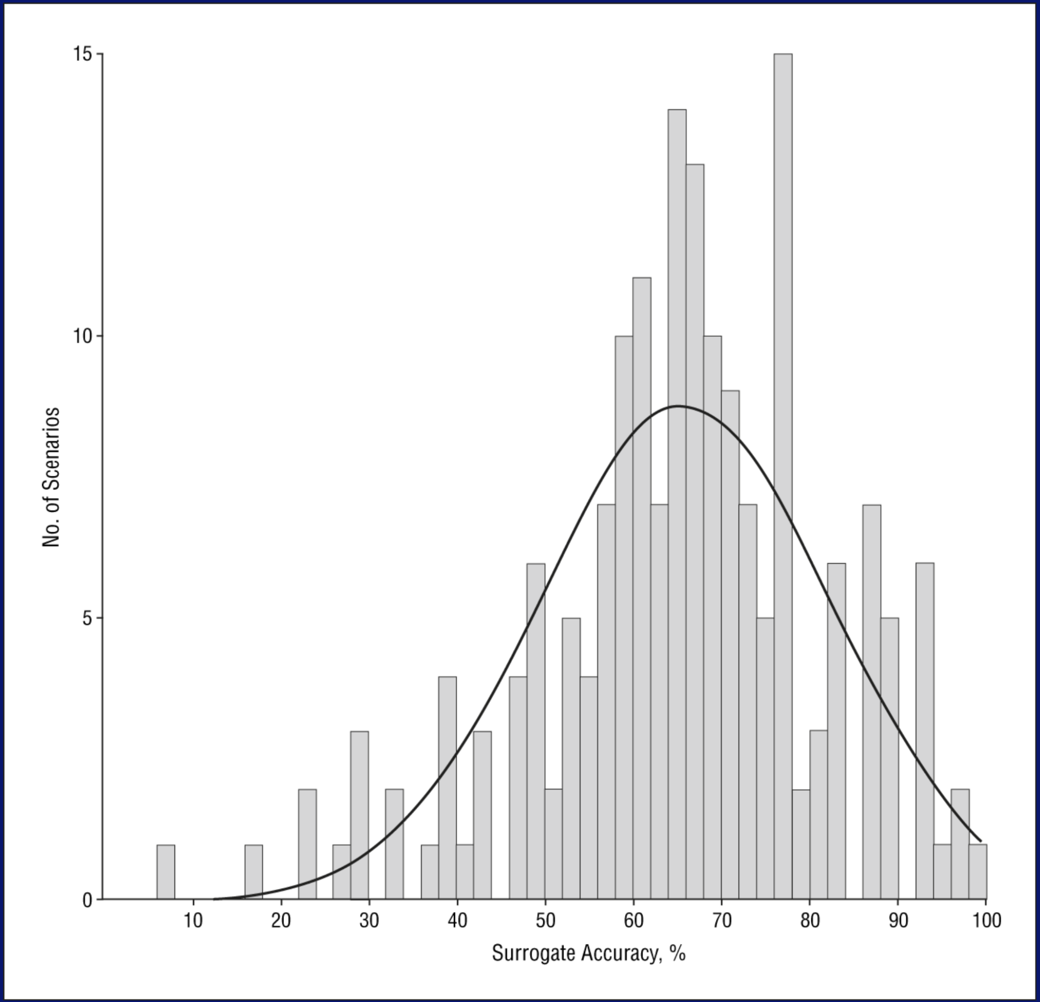
Capacity to decide for yourself

Wheight of decisions

t – trajectory of disease

The Accuracy of Surrogate Decision Makers: A Systematic Review

Arch Intern Med. 2006;166(5):493-497.



Adjusted overall accuracy of surrogates, based on meta-analysis, is 68% (95% credible interval, 63-72).

Advance Care Planning (ACP)

Definition:

Advance Care Plans are one means to ensure that patient and family preferences are negotiated, Identified and recorded before the patient is overtaken by disease.

Loss of capacity is the key to the clinical and legal constitution of ACPs and in many countries, legislation has empowered patients to refuse treatment when they come to regard it as futile or intolerable

Advance Care Planning (ACP)

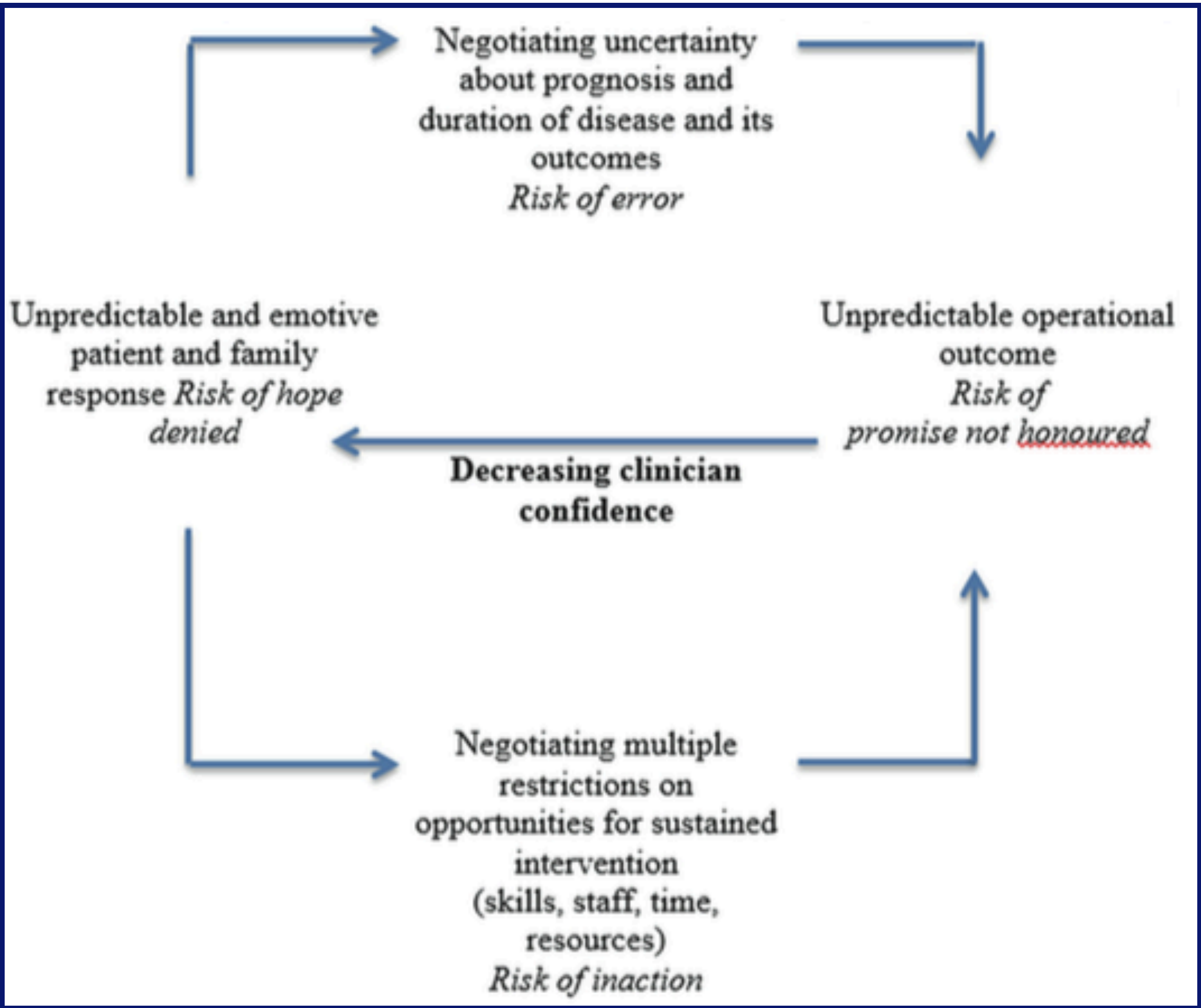
Aims:

- Provide an opportunity to consider existential and relational aspects of impending loss of self at the end of life.

- Provide an opportunity to clearly acknowledge the prospect of death, and in that context to negotiate personal preferences about future treatment decisions between patient, family members and clinicians.

- Make clear a patient's preferences about clinical actions that will follow their loss of capacity (for example, about continuation of treatment or resuscitation).

Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies



Negotiating uncertainty about prognosis and duration of disease and its outcomes
Risk of error

Unpredictable operational outcome
Risk of promise not honoured

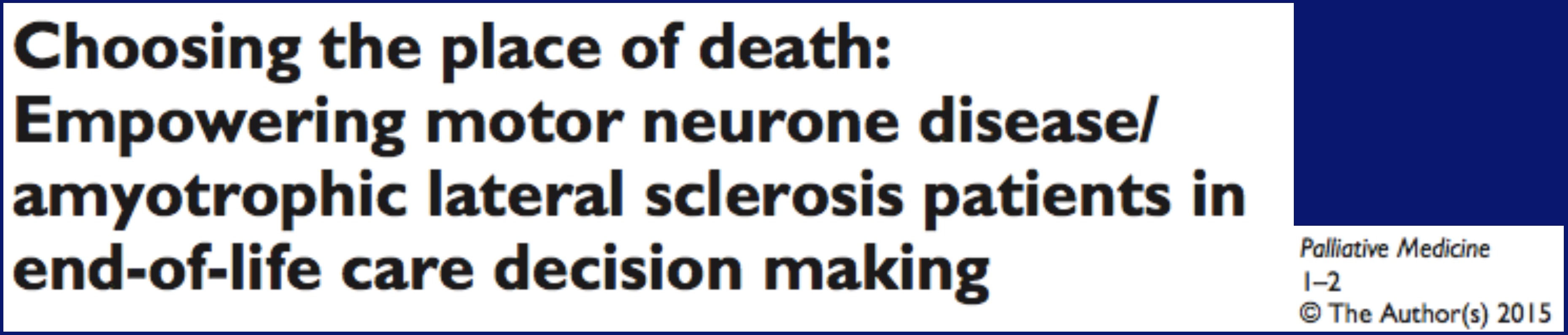
Negotiating multiple restrictions on opportunities for sustained intervention
(skills, staff, time, resources)
Risk of inaction

Unpredictable and emotive patient and family response *Risk of hope denied*

Decreasing clinician confidence

PLOS | ONE

February 13, 2015



Choosing the place of death: Empowering motor neurone disease/ amyotrophic lateral sclerosis patients in end-of-life care decision making

Palliative Medicine
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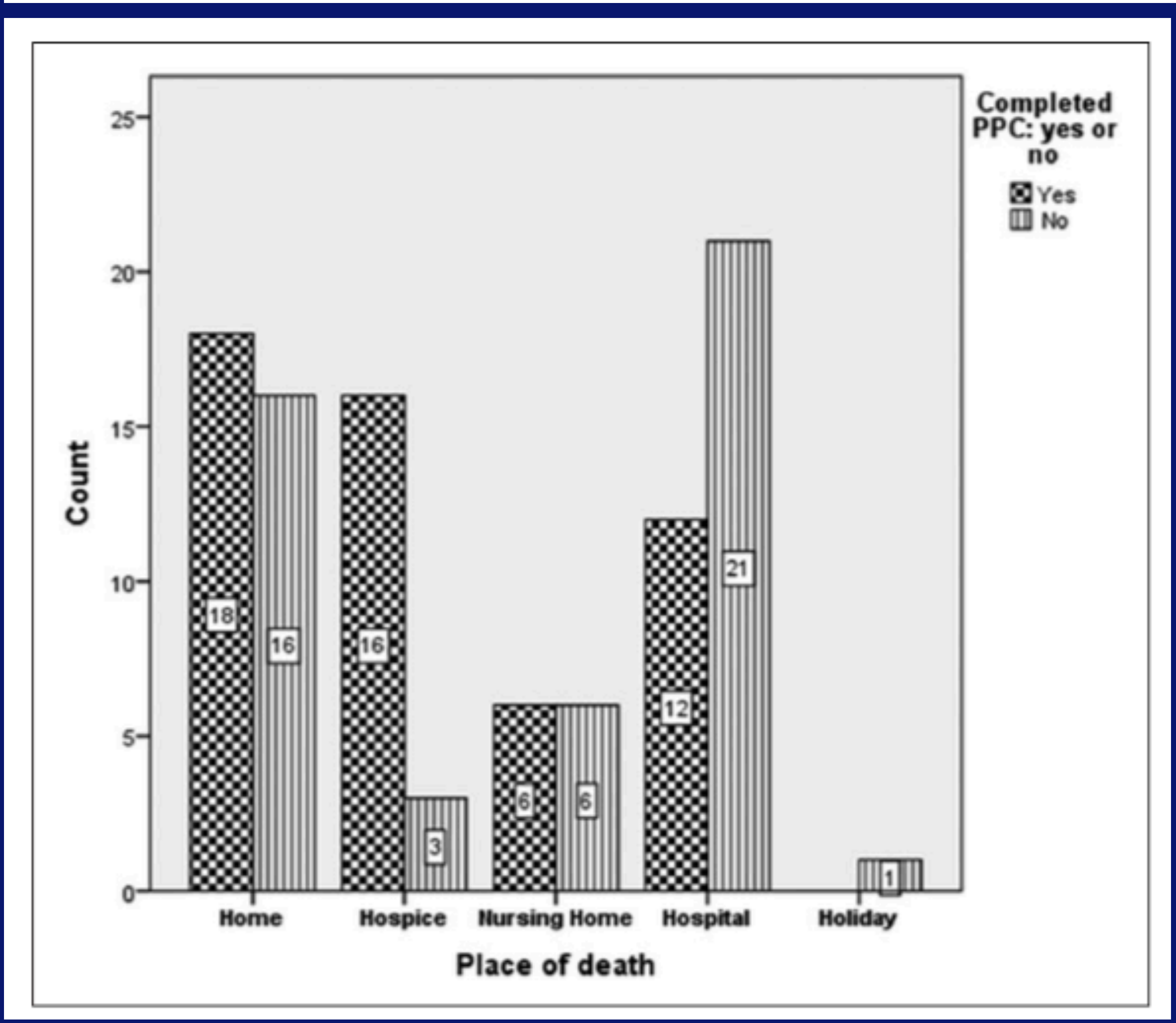

The Preferred Priorities for Care (PPC) document is a patient-held dynamic record that can be used as an ACP tool to promote discussion and documentation of wishes, preferences and priorities for care in relation to end-of-life issues.

Take home message

- There are several unique aspects of palliative and End of Life care in neurology as compared with palliative care in other patient populations..
- Therefore, it is imperative that neurologists understand, and learn to apply, the principles of palliative medicine.

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