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How to deal with wishes for hastened death

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Conflict of Interest

Pace, Andrea

- No conflict of interest to declare

Learning Objectives

- Conceptualisation of the Wish to Hasten Death
- Factors related to WTHD
- Epidemiology of WTHD
- WTHD issues in neurological diseases
- WTHD and quality of care at the End of Life
- How to support patients with persistent WTHD
- The Right to die with dignity as “Human Right”

Dignified Death

Factors related to good quality of death

- Palliative Care
- Refusal of treatment
- Advance Directives
- Limitation of treatments (Withdrawal/Withholding)
- To avoid therapeutic obstinacy

Controversial

Should dignified death include the possibility to request for euthanasia or physician assisted suicide?

What patients consider a “good death”

- Managing symptoms
- Avoiding prolungation of dying
- Achieving a sense of control
- Relieving family burden
- Strengthening of relationships

Detering CM, BMJ 2010; 340: c1345

Whish to Hasten Death

Conceptualisation

Wish to die
Desire to die
Desire to early death
Request for euthanasia
Request for physician assisted suicide

Need to differentiate between thoughts, wishes and intentions

Distinction should be made between:
(a) a generic wish to die;
(b) a WTHD (sporadic or persistent over time);
(c) the explicit manifestation of a WTHD
(d) the persistent request for PAS or euthanasia.

Monforte-Royo C, Psycho-Oncology 20: 795–804 (2011)

Whish to Hasten Death

How to measure it

WTHD phenomenon tends to vary over time, depending on the stage of disease, setting of care, psychological and social factors

Different methodologies have been used in clinical studies:

-Whish To Hasten Death Scale
-Desire for Hastened Death (DHD),
-Desire for Death Rating Scale (DDRS)
-Schedule of Attitudes Toward Hastened Death (SAHD))

Whish to Hasten Death

Epidemiology

Main issues: methodological limits, lack of reliable tools

Author	Tools	Incidence	Patients
Chochinov 1995	DDRS *	8.5%	200 palliative care
O'Mahony 2005	DDRS	33% (25%)	64 cancer pain
Kelly 2003	WTHD scale	14%	256 cancer
Rosenfeld 1999	SAHD **	12%	195 AIDS
Albert 2005	SAHD	18.8%	53 ALS
Ganzini 1998	interview	57%	100 ALS

* Desire for Death Rating Scale
**Schedule of Attitude Toward Hasten Death

Review

The wish to hasten death: a review of clinical studies

Cristina Monforte-Royo[1,2]*, Christian Villavicencio-Chávez[2,3], Joaquín Tomás-Sábado[1] and Albert Balaguer[2]

Psycho-Oncology **20**: 795–804 (2011)

Key clinical factors related to WTHD

§ physical symptoms in the form of pain, physical suffering

§ psychological distress

§ social factors, such as feeling like a burden to others

§ psycho-existential suffering

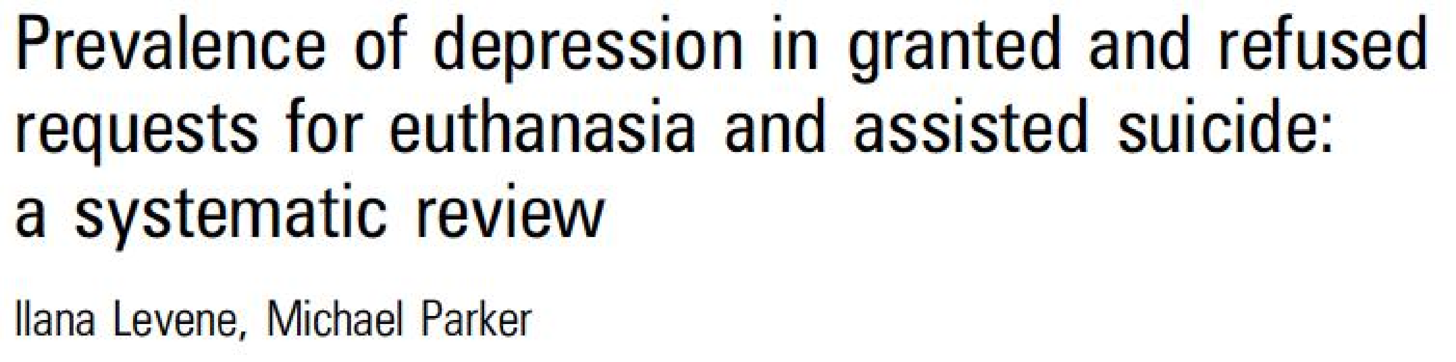
Key clinical factors related to WTHD

- physical symptoms in the form of pain, physical suffering

most studies have identified pain as an isolated factor that does not play a key role in fostering the WTHD

Some authors have introduced the concept of ‘overall physical distress’, which includes other physical signs and symptoms and whose presence is significantly associated with the emergence of a WTHD

Monforte-Royo et al, Psycho-Oncology 2011



Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review

Ilana Levene, Michael Parker

J Med Ethics 2011;**37**:205–211

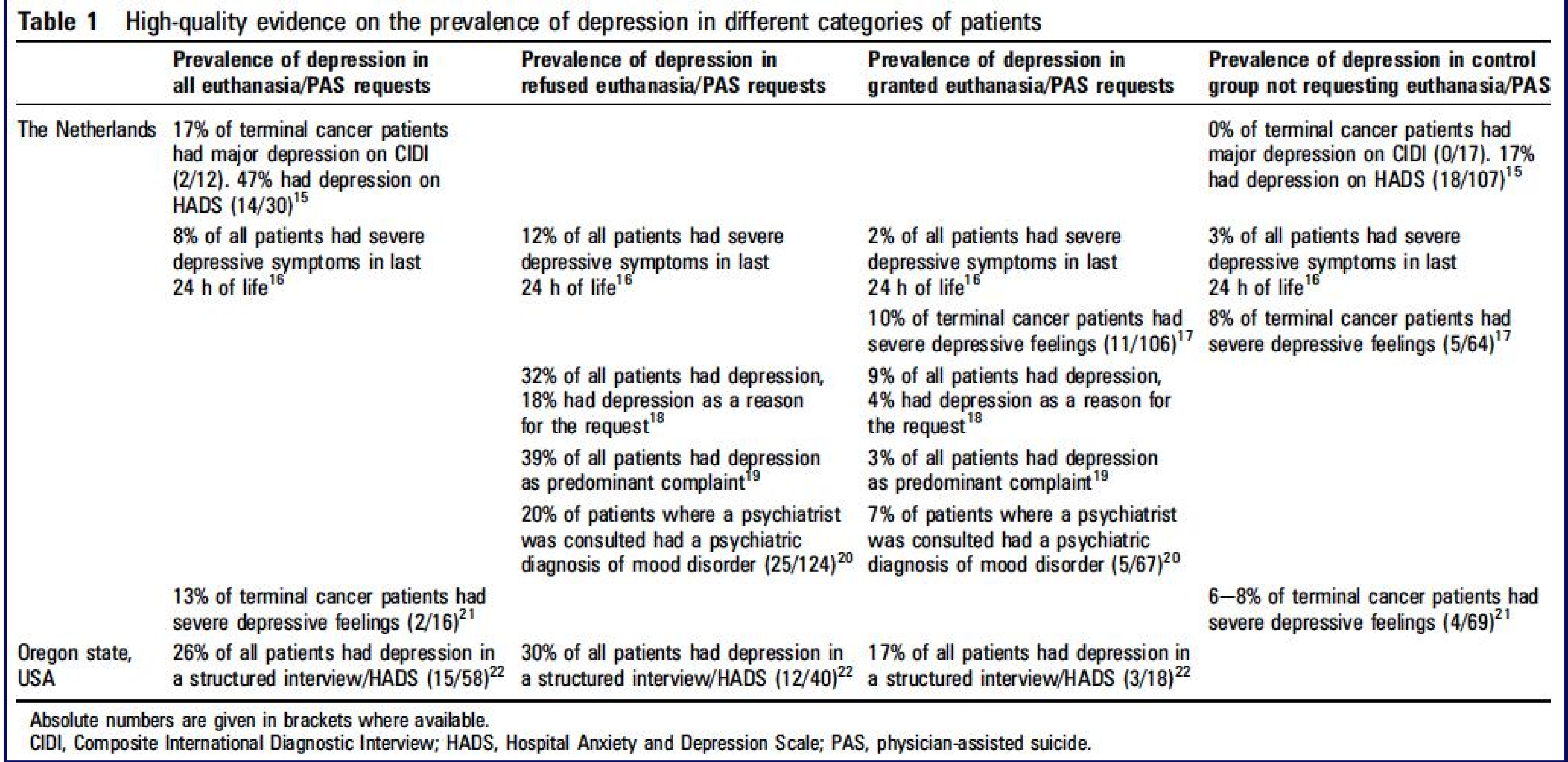
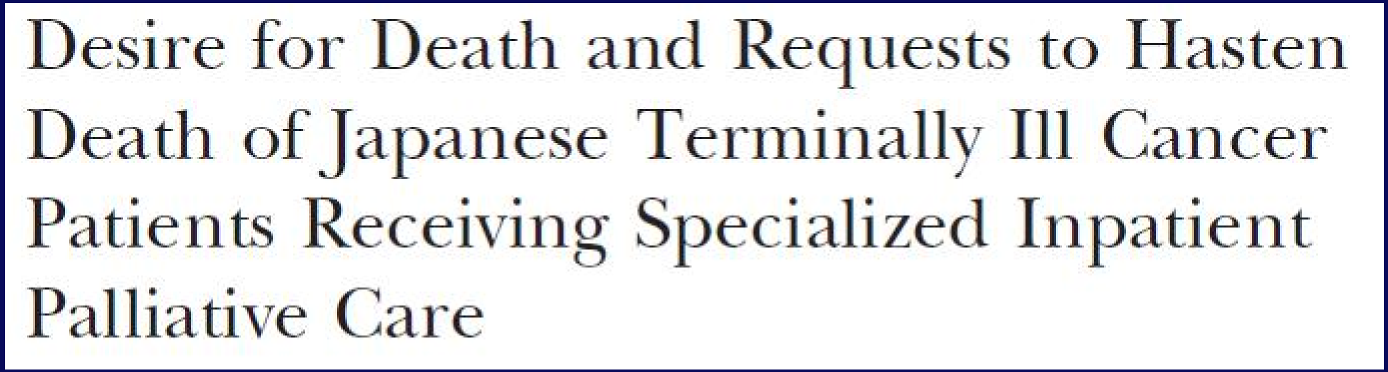


Table 1 High-quality evidence on the prevalence of depression in different categories of patients

	Prevalence of depression in all euthanasia/PAS requests	**Prevalence of depression in refused euthanasia/PAS requests**	**Prevalence of depression in granted euthanasia/PAS requests**	**Prevalence of depression in control group not requesting euthanasia/PAS**
The Netherlands	17% of terminal cancer patients had major depression on CIDI (2/12). 47% had depression on HADS (14/30)[15]			0% of terminal cancer patients had major depression on CIDI (0/17). 17% had depression on HADS (18/107)[15]
	8% of all patients had severe depressive symptoms in last 24 h of life[16]	12% of all patients had severe depressive symptoms in last 24 h of life[16]	2% of all patients had severe depressive symptoms in last 24 h of life[16]	3% of all patients had severe depressive symptoms in last 24 h of life[16]
			10% of terminal cancer patients had severe depressive feelings (11/106)[17]	8% of terminal cancer patients had severe depressive feelings (5/64)[17]
		32% of all patients had depression, 18% had depression as a reason for the request[18]	9% of all patients had depression, 4% had depression as a reason for the request[18]	
		39% of all patients had depression as predominant complaint[19]	3% of all patients had depression as predominant complaint[19]	
		20% of patients where a psychiatrist was consulted had a psychiatric diagnosis of mood disorder (25/124)[20]	7% of patients where a psychiatrist was consulted had a psychiatric diagnosis of mood disorder (5/67)[20]	
	13% of terminal cancer patients had severe depressive feelings (2/16)[21]			6–8% of terminal cancer patients had severe depressive feelings (4/69)[21]
Oregon state, USA	26% of all patients had depression in a structured interview/HADS (15/58)[22]	30% of all patients had depression in a structured interview/HADS (12/40)[22]	17% of all patients had depression in a structured interview/HADS (3/18)[22]	

Absolute numbers are given in brackets where available.
CIDI, Composite International Diagnostic Interview; HADS, Hospital Anxiety and Depression Scale; PAS, physician-assisted suicide.



Desire for Death and Requests to Hasten Death of Japanese Terminally Ill Cancer Patients Receiving Specialized Inpatient Palliative Care

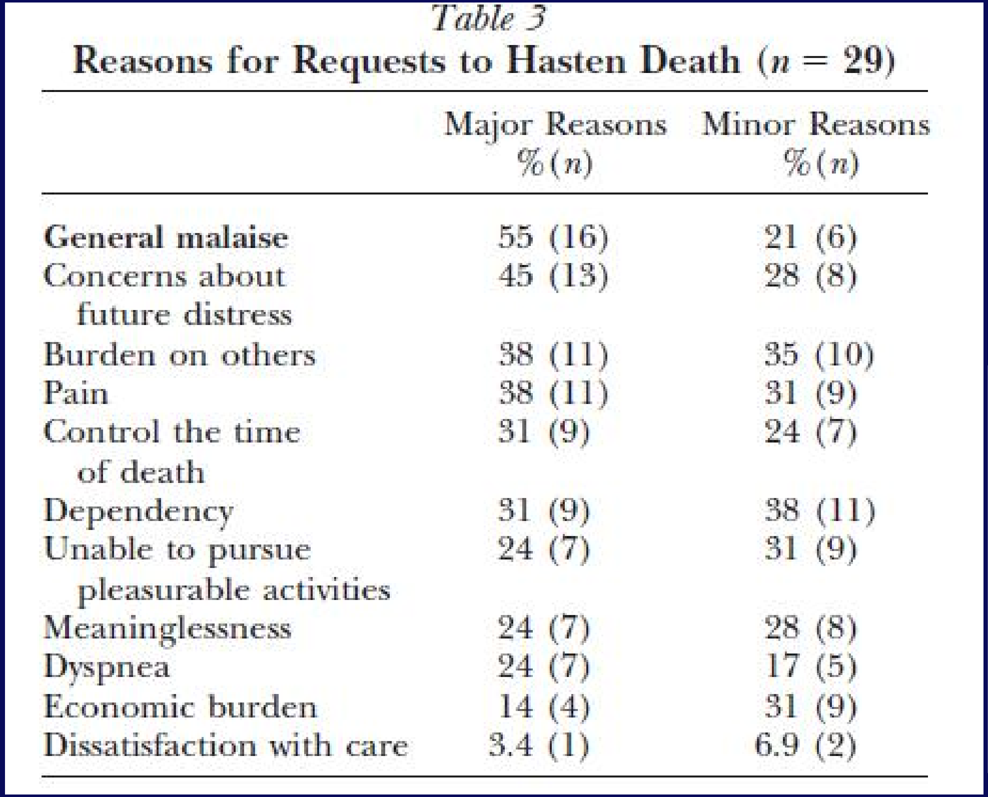


Table 3

Reasons for Requests to Hasten Death (*n* = 29)

	Major Reasons % (*n*)	Minor Reasons % (*n*)
General malaise	55 (16)	21 (6)
Concerns about future distress	45 (13)	28 (8)
Burden on others	38 (11)	35 (10)
Pain	38 (11)	31 (9)
Control the time of death	31 (9)	24 (7)
Dependency	31 (9)	38 (11)
Unable to pursue pleasurable activities	24 (7)	31 (9)
Meaninglessness	24 (7)	28 (8)
Dyspnea	24 (7)	17 (5)
Economic burden	14 (4)	31 (9)
Dissatisfaction with care	3.4 (1)	6.9 (2)

- Nationwide survey of 500 caregivers
- 21% desire to die
- 10% request to hasten death

"However, some patients with a strong wish to control the time of death might not receive benefit from conventional palliative care."

Journal of Pain and Symptom Management Vol. 27 No. 1 January 2004

Temporal stability of WTHD

The majority of WTHD requests are, paradoxically, a request for help with living

Patients admitted to a palliative care unit and who had expressed a WTHD changed their minds after feeling that their concerns had been heard

The WTHD becomes less strong when the patient perceives a degree of hope in the treatment and care being received

What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients

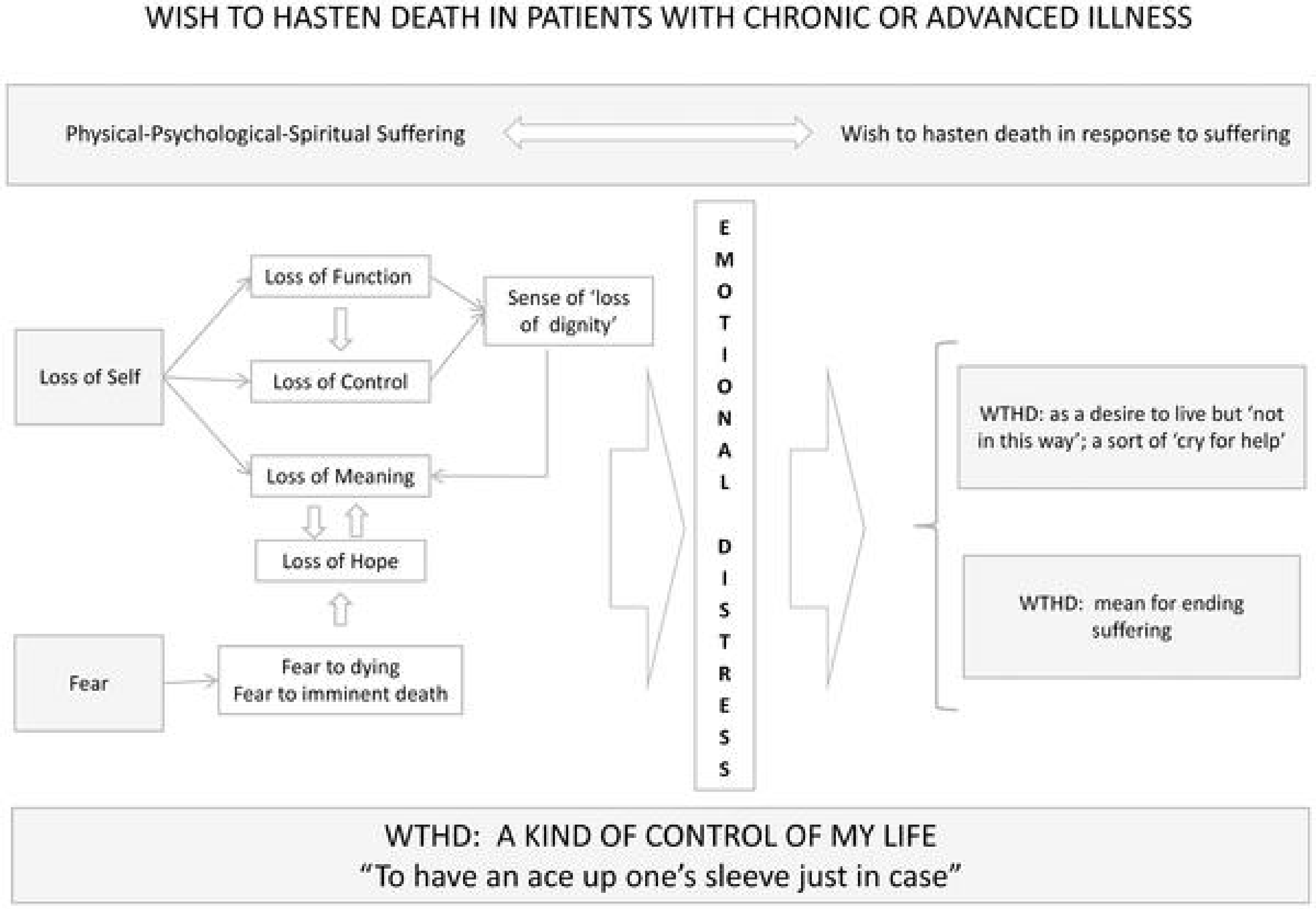
Cristina Monforte-Royo[1,6], Christian Villavicencio-Chávez[2,6], Joaquin Tomás-Sábado[3], Vinita Mahtani-Chugani[4,5], Albert Balaguer[1,6*]

Although quantitative research may provide highly valuable information about the WTHD, it is difficult for such methods to fully penetrate the complex reality experienced by the patient who wishes to die

This method is specifically designed to understand subjective experience by focusing on the description and interpretation of the meaning of a WTHD phenomenon

http://www.plosone.org/article/info:doi/10.1371/journal.pone.0037117

Explanatory model of WTHD.



Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, et al. (2012) What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients.
PLoS ONE 7(5): e37117. doi:10.1371/journal.pone.0037117
http://www.plosone.org/article/info:doi/10.1371/journal.pone.0037117

Whish to Hasten Death

Explanatory model

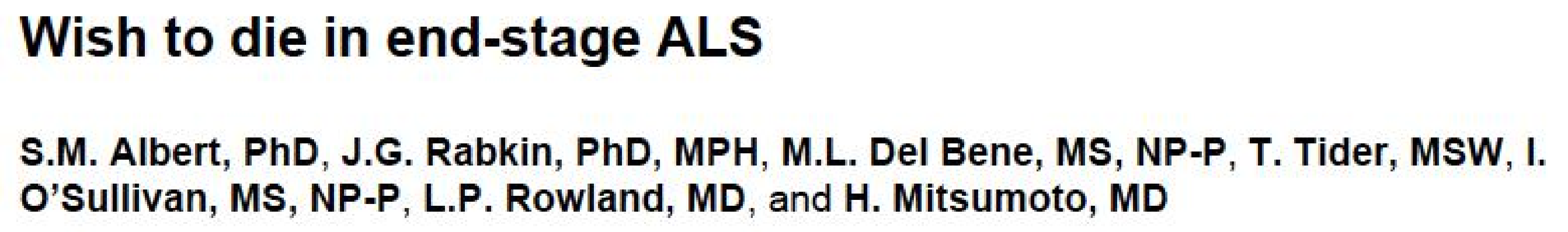
- *“WTHD is a reactive phenomenon, a response to multi-dimensional suffering”*

- *“WTHD is a multifactorial construct with multiple meanings that do not necessarely imply a genuine desire to hasten one’s death”*

Monforte-Royo et al, PLoS ONE 2012

I am not afraid of death,
I just don't want to be there when it happens.

Woody Allen



Wish to die in end-stage ALS

S.M. Albert, PhD, J.G. Rabkin, PhD, MPH, M.L. Del Bene, MS, NP-P, T. Tider, MSW, I. O'Sullivan, MS, NP-P, L.P. Rowland, MD, and **H. Mitsumoto, MD**

Neurology. 2005 July 12; 65(1): 68–74.

80 hospice-eligible ALS patients assessed at monthly intervals until death

10 (18.9%) expressed the wish to die and three (5.7%) requested sedatives explicitly to hasten dying

The wish to die was associated with pessimism, less comfort in religion, and greater hopelessness, but not with depression.

"Assessing for depression is always a piece of the assessment puzzle, but, trying to understand the patient's dilemma and view of the present and future requires a much broader inquiry into existential and personal domains"

ALS, depression, and desire for a hastened death: (How) are they related? Commentary by Timothy E. Quill,

Neurology 2005

EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE AMONG PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS IN THE NETHERLANDS

JAN H. VELDINK, M.D., JOHN H.J. WOKKE, M.D., PH.D., GERRIT VAN DER WAL, M.D., PH.D.,
J.M.B. VIANNEY DE JONG, M.D., PH.D., AND LEONARD H. VAN DEN BERG, M.D., PH.D.

N Engl J Med, Vol. 346, No. 21

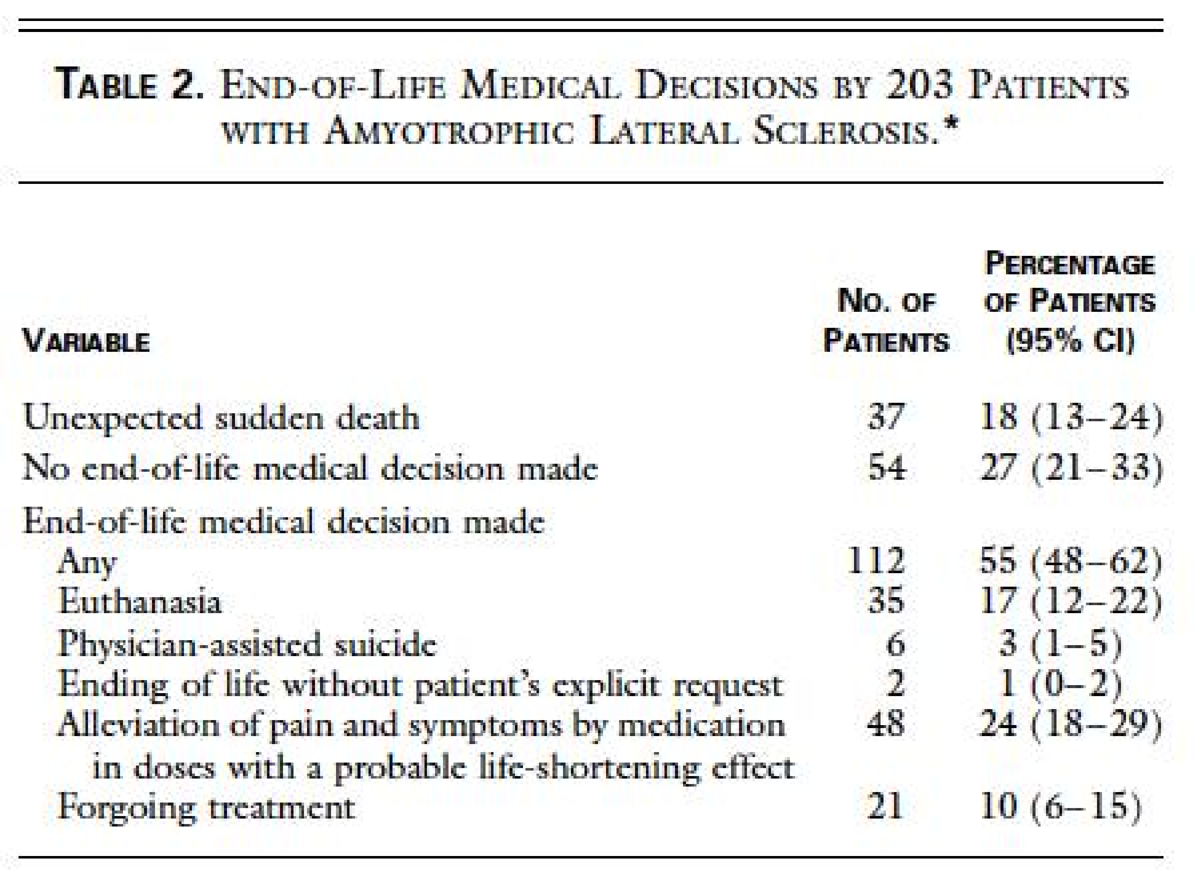


TABLE 2. END-OF-LIFE MEDICAL DECISIONS BY 203 PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS.*

VARIABLE	NO. OF PATIENTS	PERCENTAGE OF PATIENTS (95% CI)
Unexpected sudden death	37	18 (13–24)
No end-of-life medical decision made	54	27 (21–33)
End-of-life medical decision made		
Any	112	55 (48–62)
Euthanasia	35	17 (12–22)
Physician-assisted suicide	6	3 (1–5)
Ending of life without patient's explicit request	2	1 (0–2)
Alleviation of pain and symptoms by medication in doses with a probable life-shortening effect	48	24 (18–29)
Forgoing treatment	21	10 (6–15)

Trends and determinants of end-of-life practices in ALS in the Netherlands

M. Maessen, MSc, J. H. Veldink, MD, PhD, B. D. Onwuteaka-Philipsen, PhD, J. M. de Vries, MD, J.H.J. Wokke, MD, PhD, G. van der Wal, MD, PhD and L. H. van den Berg, MD, PhD

High rate of euthanasia or PAS in ALS patients (16.8%)

Stable over a period of 10 years (1994-2005)

Reasons for WTHD: no chance of improvement, loss of dignity, being dependent.

No “slippery slope” since 2002!

NEUROLOGY 2009

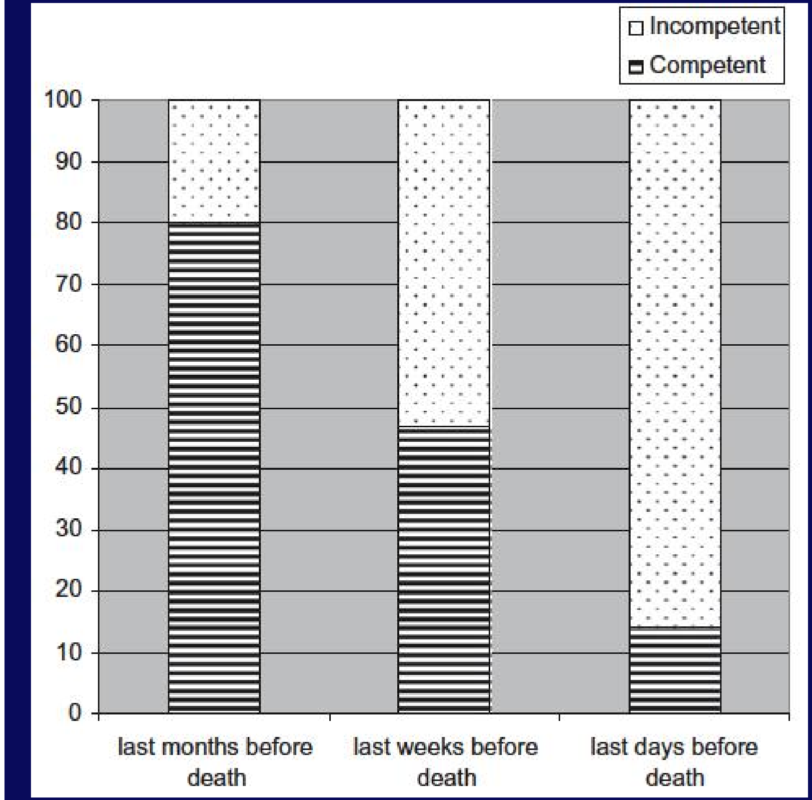
Decision-making in the end-of-life phase of high-grade glioma patients

Eefje M. Sizoo [a,], H. Roeline W. Pasman [b], Janine Buttolo [a], Jan J. Heimans [a], Martin Klein [c], Luc Deliens [b,d], Jaap C. Reijneveld [a,e], Martin J.B. Taphoorn [a,f]*

Table 2 – Type of end of life preferences expressed by the patient according to physician ($n = 101$).

Any wishes expressed	60%
*Specific wishes**:	
Life prolonging treatment	
In favour	2%
Opposed	36%
No opinion/not discussed	62%
Admission to hospital	
In favour	4%
Opposed to	45%
Not discussed/no opinion/not applicable	51%
Palliative sedation	
In favour	24%
Opposed to	5%
Not discussed/no opinion	71%
Euthanasia	
In favour	18%
Opposed to	20%
Not discussed/no opinion	62%

* Multiple wishes per patient possible.



EUROPEAN JOURNAL OF CANCER 48 (2012) 226–232

The End-of-Life Phase of High-Grade Glioma Patients: Dying With Dignity?

EEFJE M. SIZOO,[a] MARTIN J.B. TAPHOORN,[a,b] BERNARD UITDEHAAG,[a,c] JAN J. HEIMANS,[a] LUC DELIENS,[d,e] JAAP C. REIJNEVELD,
H. ROELINE W. PASMAN[d]

The Oncologist 2013;18:198–203

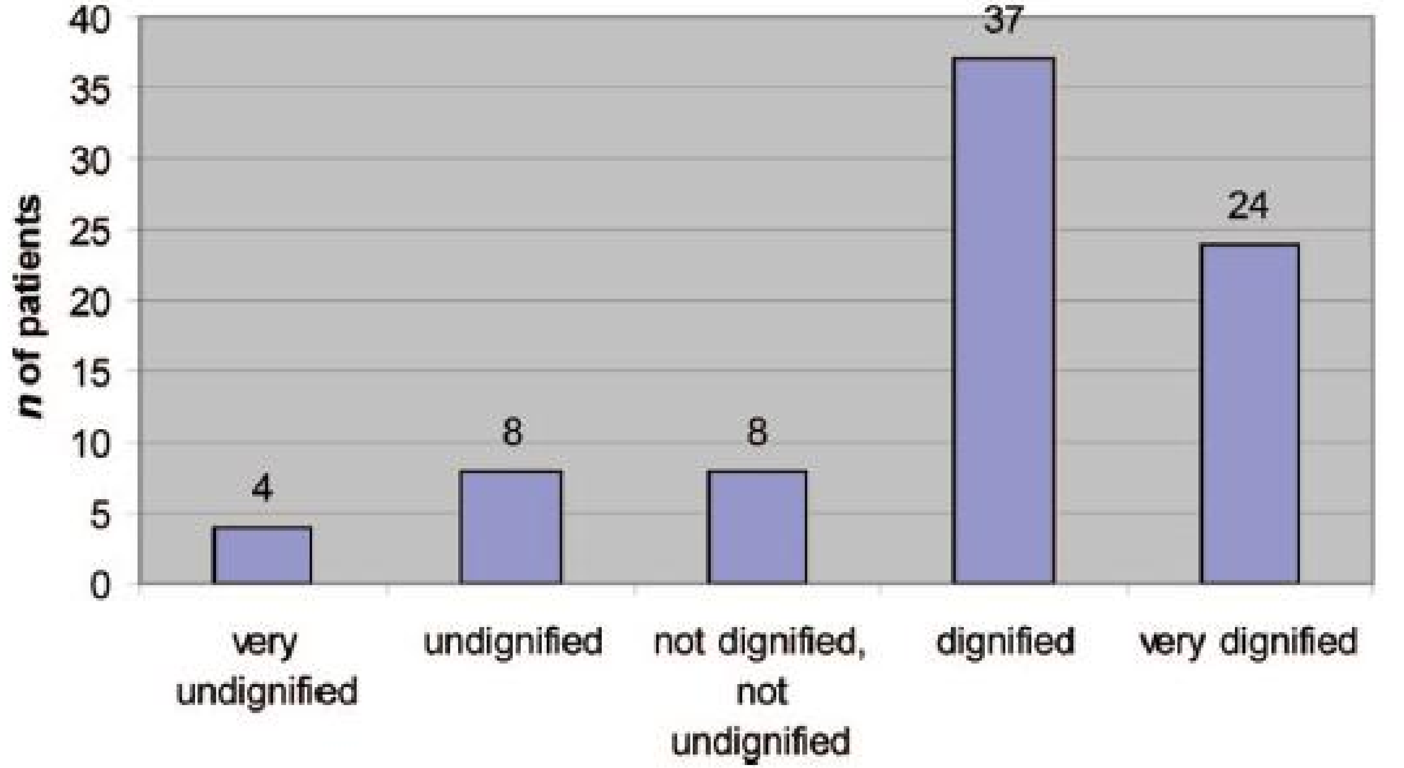


Figure 1. Dignified dying in high-grade glioma patients according to relatives ($n = 81$).

Home care for brain tumor patients

Activity

Equipe

- 5 nurses
- 3 physioter.
- 2 neurologist
- 2 psychologist
- 1 social worker
- 1 data manager

§ Nursing

§ Home rehabilitation

§ Supportive therapy

§ Symptoms control

§ Psychological support for patients and family

§ Social work help

§ Continuity of care from hospital to district services

§ End of life support

§ Bereavment support

End of life care in Brain Tumors

Major issues

- Symptoms control (epilepsy, delirium, dysphagia..)
- Steroid reduction/withdrawal
- Nutrition and Hydration
- Palliative sedation
- Advance directives
- EoL treatment decisions in non-competent patients

End of life issues in brain tumor patients

Pace et al, J Neuronc 2009

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Eol treatment decisions issues in Brain Tumors

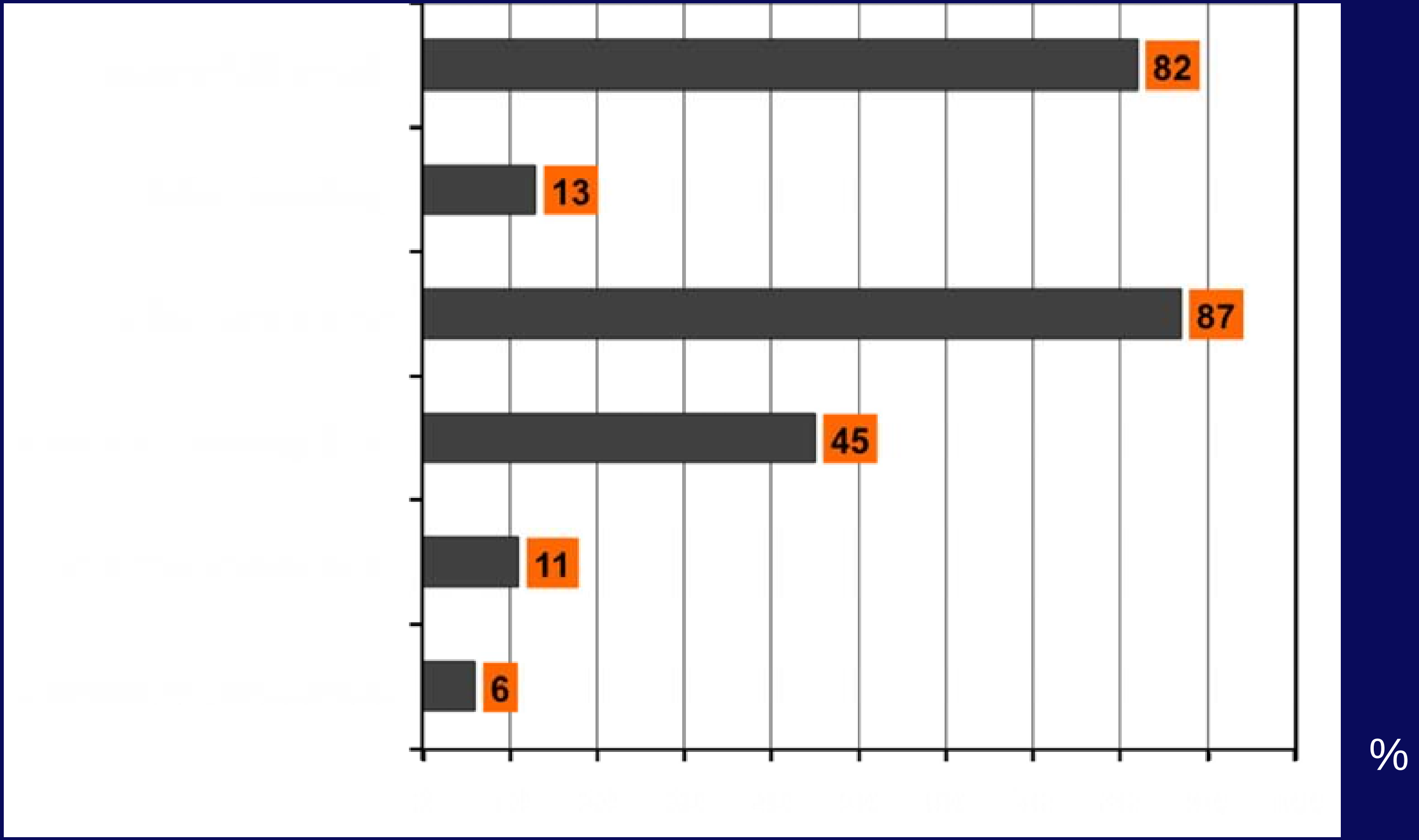
§ No-treatment decisions

- Steroid reduction /interruption
- Artificial nutrition witholding

§ Refractory symptoms alleviation

- Palliative sedation with opioids, neuroleptics, BDZs

EoL decisions in 247 Brain Tumor patients dying at home



End of life issues in brain tumor patients J Neuronc 2009

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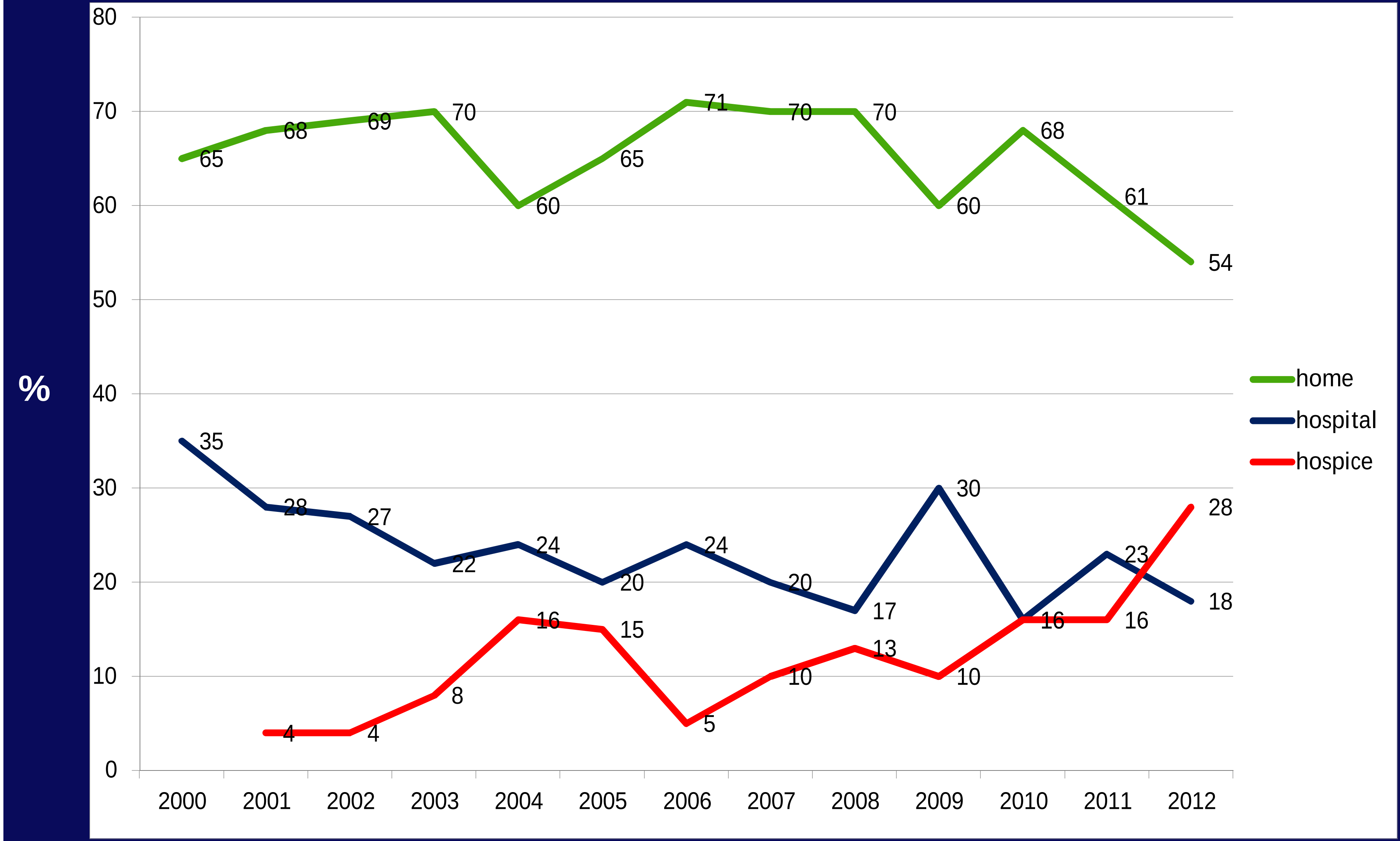
Place of death in 357 patients

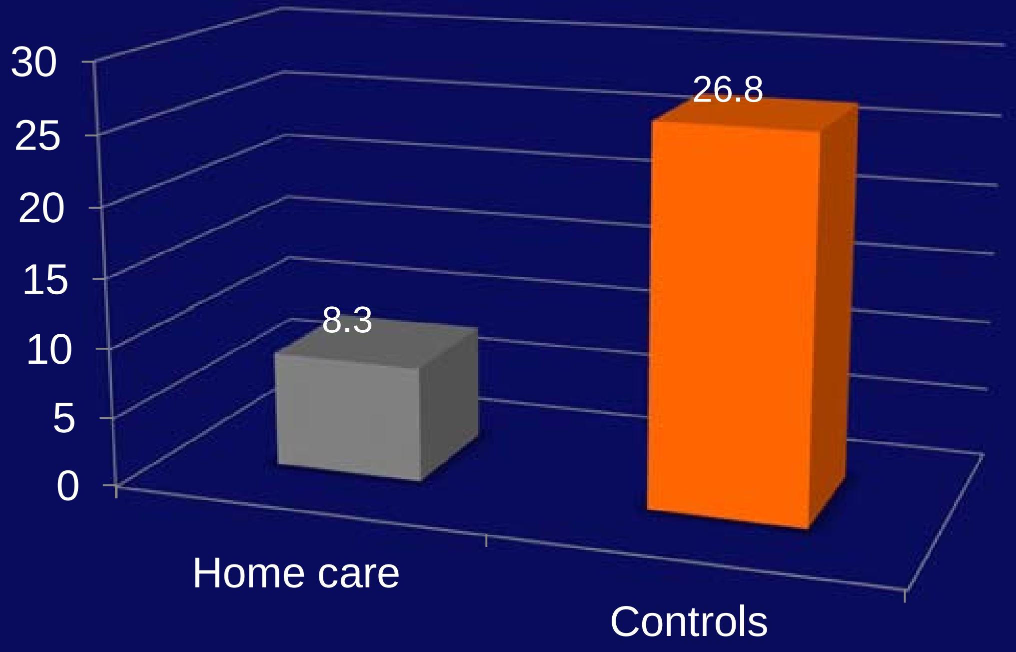
Palliative home care Unit for BT patients



Quality of Care and Rehospitalization Rate in the Last Stage of Disease in Brain Tumor Patients Assisted at Home: A Cost Effectiveness Study

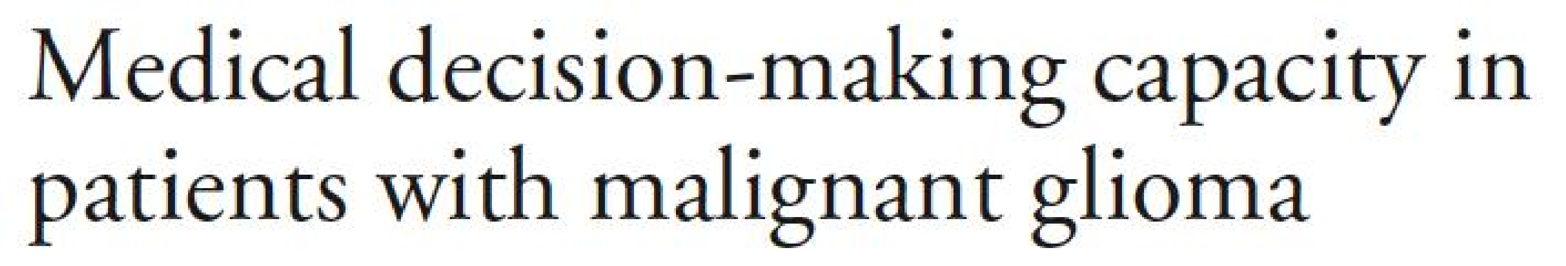
JOURNAL OF PALLIATIVE MEDICINE
Volume 15, Number 2, 2012

% re-hospitalization

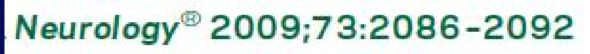


p < 0.009

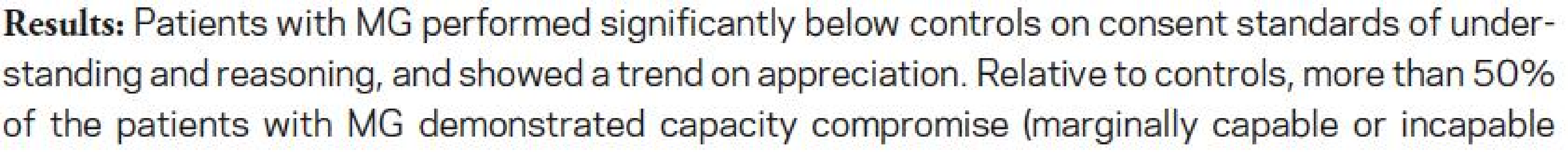
Pace A et al: J Pall Med 2012



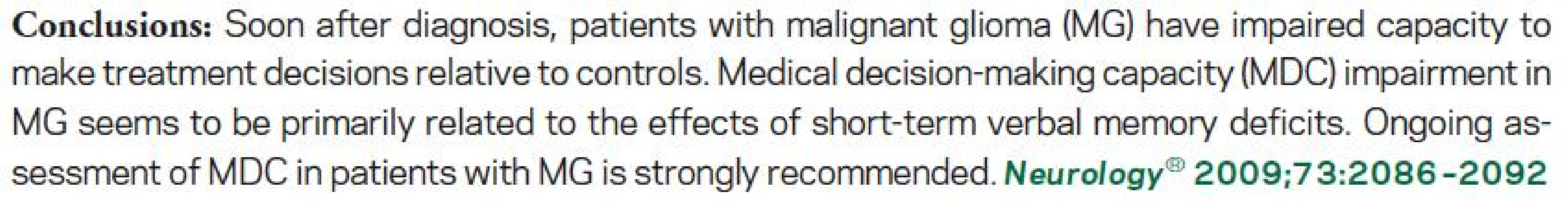
Medical decision-making capacity in patients with malignant glioma



Neurology® 2009;73:2086-2092

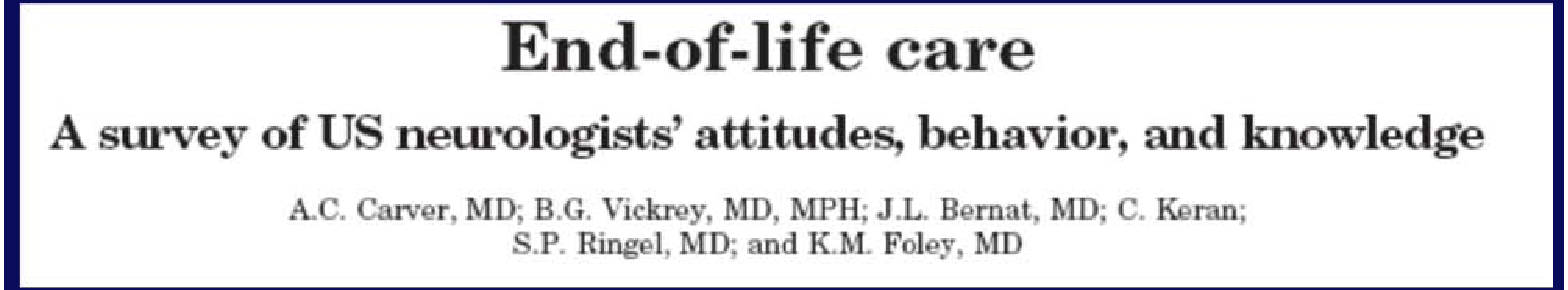


Results: Patients with MG performed significantly below controls on consent standards of understanding and reasoning, and showed a trend on appreciation. Relative to controls, more than 50% of the patients with MG demonstrated capacity compromise (marginally capable or incapable



Conclusions: Soon after diagnosis, patients with malignant glioma (MG) have impaired capacity to make treatment decisions relative to controls. Medical decision-making capacity (MDC) impairment in MG seems to be primarily related to the effects of short-term verbal memory deficits. Ongoing assessment of MDC in patients with MG is strongly recommended. *Neurology*® 2009;73:2086-2092

Neurology 1999;53:284



End-of-life care

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

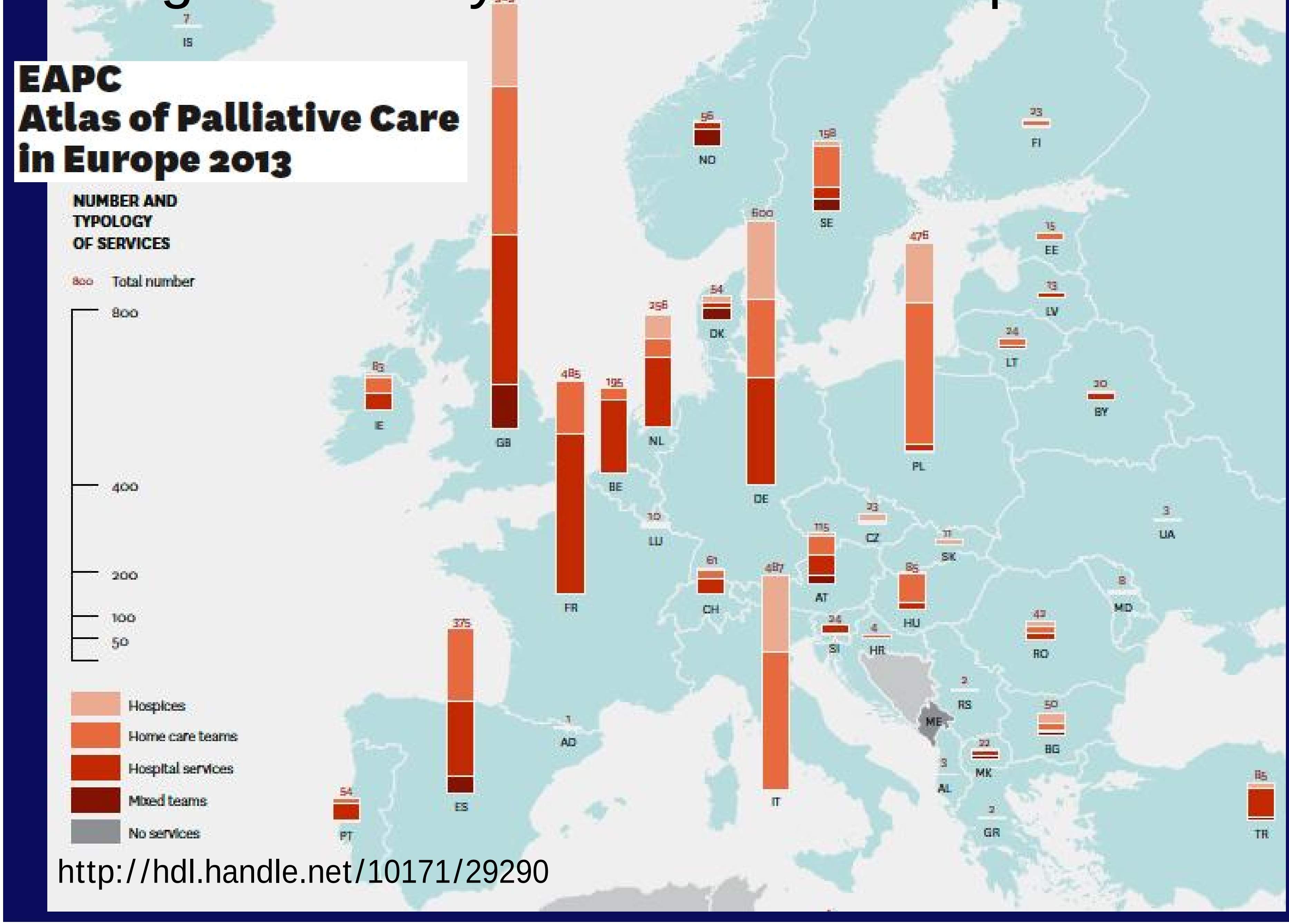
A.C. Carver, MD; B.G. Vickrey, MD, MPH; J.L. Bernat, MD; C. Keran;
S.P. Ringel, MD; and K.M. Foley, MD

- 353 neurologists
- 152 neuro-oncologists
- ALS specialists

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

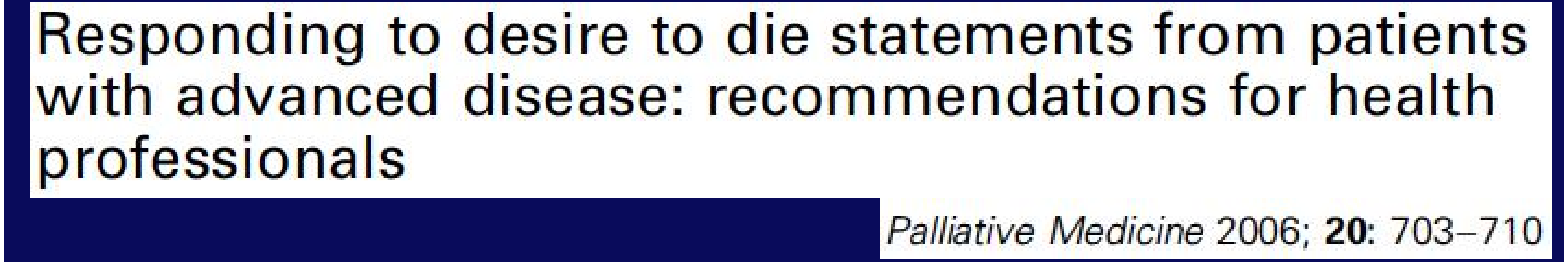
"..there is a great need for education in palliative care and end-of-life decision-making.."

Large variability in Palliative Care provision



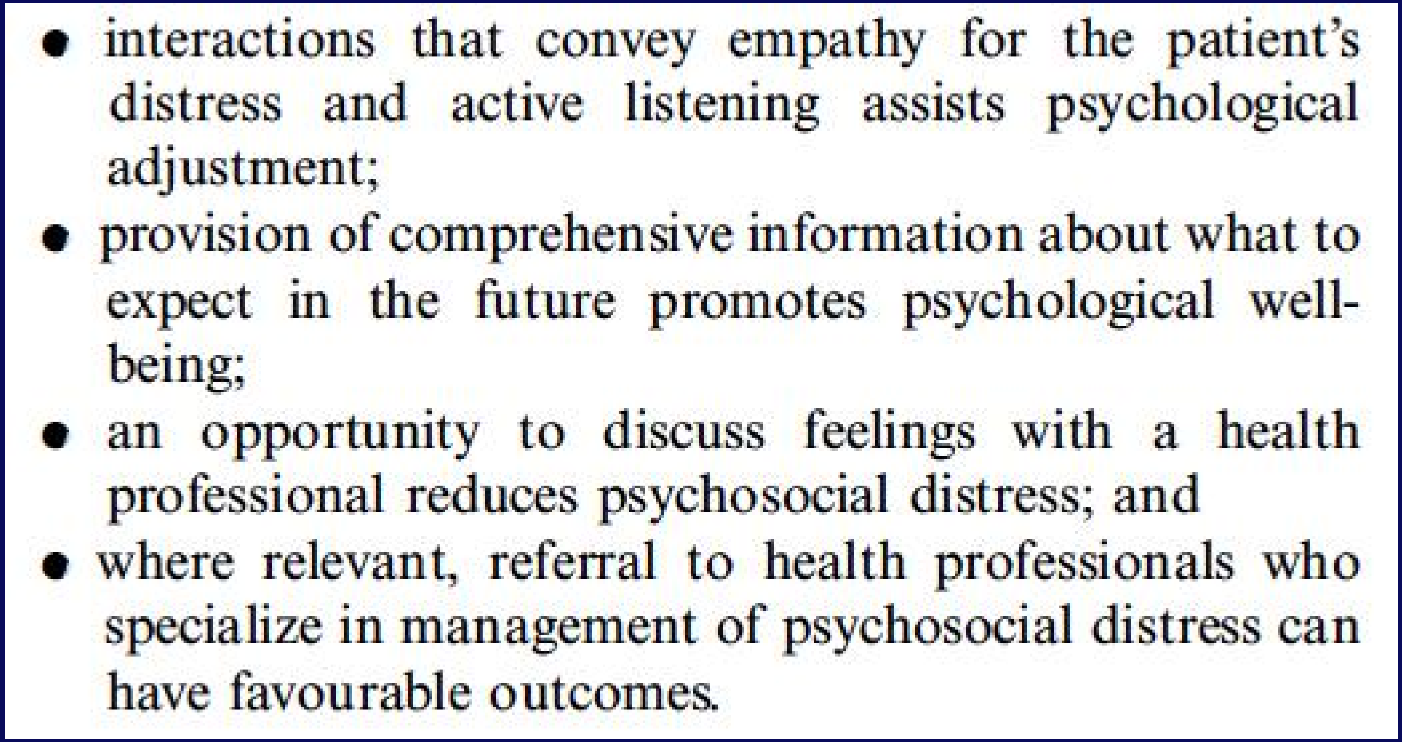
EAPC
Atlas of Palliative Care in Europe 2013

http://hdl.handle.net/10171/29290



Responding to desire to die statements from patients with advanced disease: recommendations for health professionals

Palliative Medicine 2006; **20:** 703–710



- interactions that convey empathy for the patient's distress and active listening assists psychological adjustment;
- provision of comprehensive information about what to expect in the future promotes psychological well-being;
- an opportunity to discuss feelings with a health professional reduces psychosocial distress; and
- where relevant, referral to health professionals who specialize in management of psychosocial distress can have favourable outcomes.

Multidimensional evaluation of requests to hasten death

- Clarify wich questions underlying
- Evaluate decision-making capacity
- Intensify treatment of uncontrolled symptoms
- Explore dimensions that may contribute to unbearable suffering
- Support the patient request

Quill T, J Pall Med 2008

What to do with patients persisting in their request

- decision-making process
- nonabandonment issue
- consider possibilities:
  - -withdrawal of life-sustaining treatments
  - -voluntary withdrawal of oral intake
  - -sedation for intractable symptoms
  - -assisted suicide

Quill T, J Pall Med 2008

What to do with patients persisting in their request / 2

physician issues

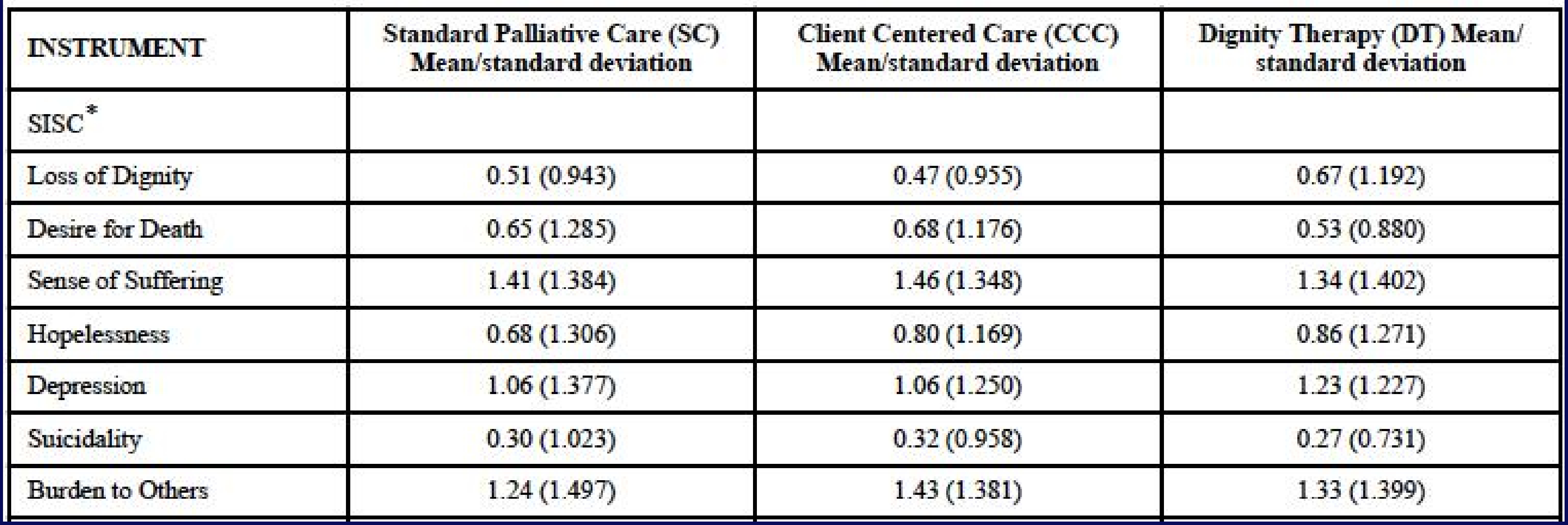
- reflect on your personal feeelings
- consider second opinion/ethical consultation
- balance integrity of your personal principles and nonabandonment

Quill T, J Pall Med 2008

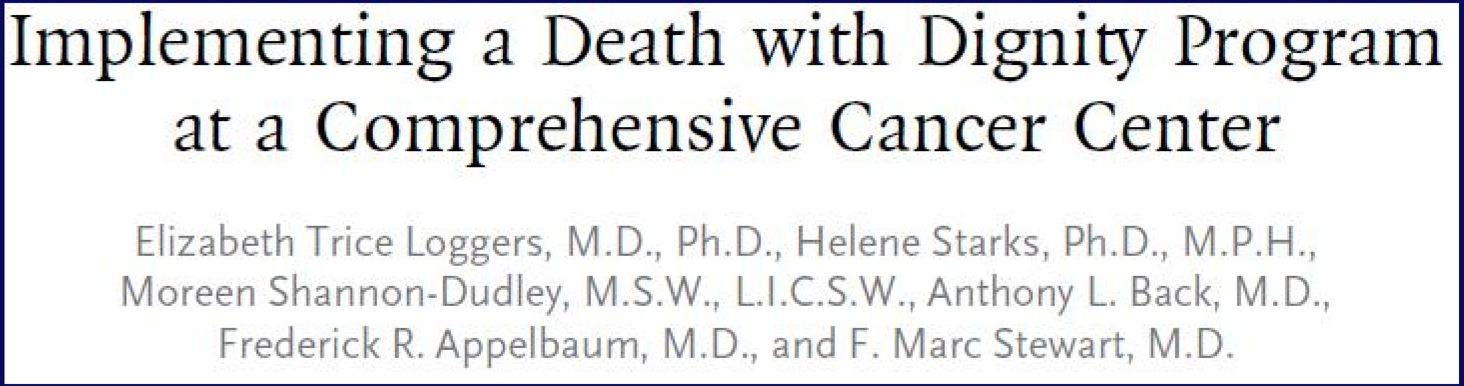
The effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial

Lancet Oncol. 2011 August ; 12(8): 753–762.

Dignity Therapy, a unique, individualized, brief psychotherapy, was developed for the purpose of relieving distress and enhancing end-of-life experience for patients nearing death



INSTRUMENT	Standard Palliative Care (SC) Mean/standard deviation	Client Centered Care (CCC) Mean/standard deviation	Dignity Therapy (DT) Mean/ standard deviation
SISC*			
Loss of Dignity	0.51 (0.943)	0.47 (0.955)	0.67 (1.192)
Desire for Death	0.65 (1.285)	0.68 (1.176)	0.53 (0.880)
Sense of Suffering	1.41 (1.384)	1.46 (1.348)	1.34 (1.402)
Hopelessness	0.68 (1.306)	0.80 (1.169)	0.86 (1.271)
Depression	1.06 (1.377)	1.06 (1.250)	1.23 (1.227)
Suicidality	0.30 (1.023)	0.32 (0.958)	0.27 (0.731)
Burden to Others	1.24 (1.497)	1.43 (1.381)	1.33 (1.399)



Implementing a Death with Dignity Program at a Comprehensive Cancer Center

Elizabeth Trice Loggers, M.D., Ph.D., Helene Starks, Ph.D., M.P.H.,
Moreen Shannon-Dudley, M.S.W., L.I.C.S.W., Anthony L. Back, M.D.,
Frederick R. Appelbaum, M.D., and F. Marc Stewart, M.D.

N Engl J Med 2013;368:1417-24.

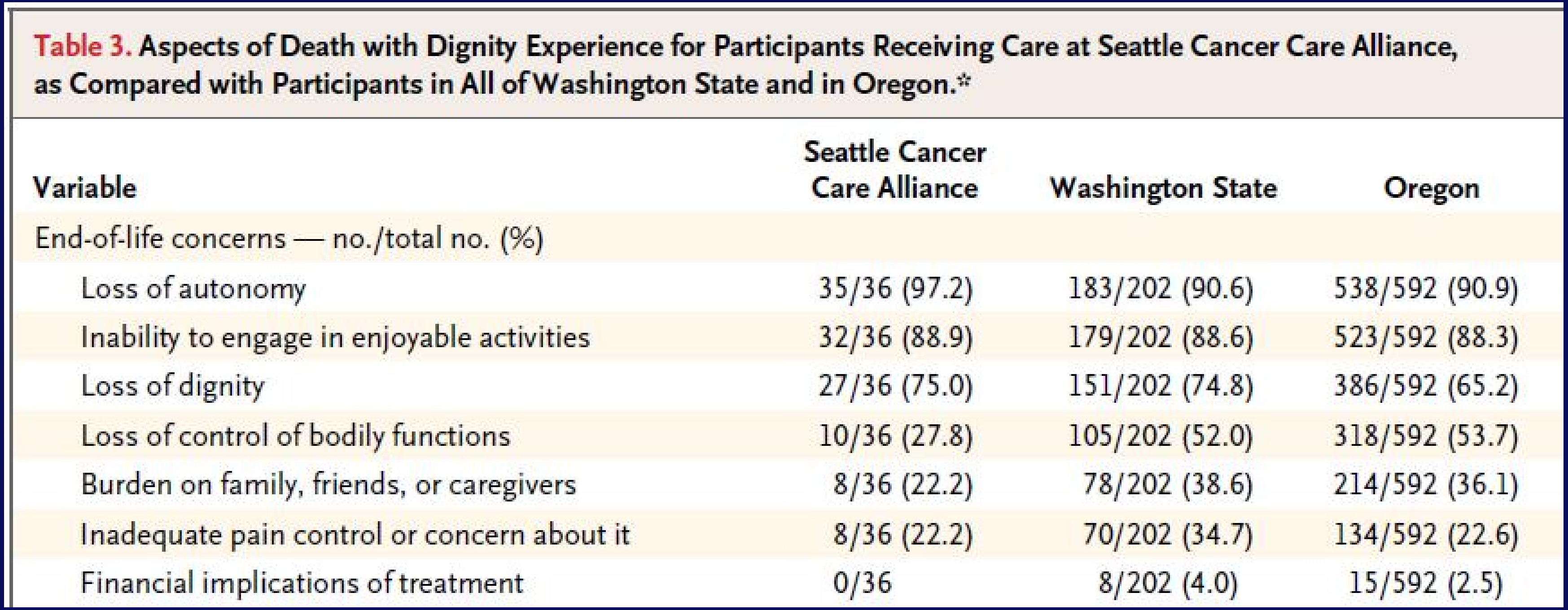


Table 3. Aspects of Death with Dignity Experience for Participants Receiving Care at Seattle Cancer Care Alliance, as Compared with Participants in All of Washington State and in Oregon.*

Variable	Seattle Cancer Care Alliance	Washington State	Oregon
End-of-life concerns — no./total no. (%)			
Loss of autonomy	35/36 (97.2)	183/202 (90.6)	538/592 (90.9)
Inability to engage in enjoyable activities	32/36 (88.9)	179/202 (88.6)	523/592 (88.3)
Loss of dignity	27/36 (75.0)	151/202 (74.8)	386/592 (65.2)
Loss of control of bodily functions	10/36 (27.8)	105/202 (52.0)	318/592 (53.7)
Burden on family, friends, or caregivers	8/36 (22.2)	78/202 (38.6)	214/592 (36.1)
Inadequate pain control or concern about it	8/36 (22.2)	70/202 (34.7)	134/592 (22.6)
Financial implications of treatment	0/36	8/202 (4.0)	15/592 (2.5)

114 inquired Death for Dignity program (2009-2011)
44 (36.6%) did not pursue the program
30 (26.3%) initiated the process but did not conclude or die before completion

“Slippery slope” concern

If physician-assisted suicide (PAS) and/or voluntary active euthanasia were legalised, would this disproportionately affect people in ‘‘vulnerable’’ groups?

Quill T, J Pall Med 2008

LAW, ETHICS AND MEDICINE

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ''vulnerable'' groups

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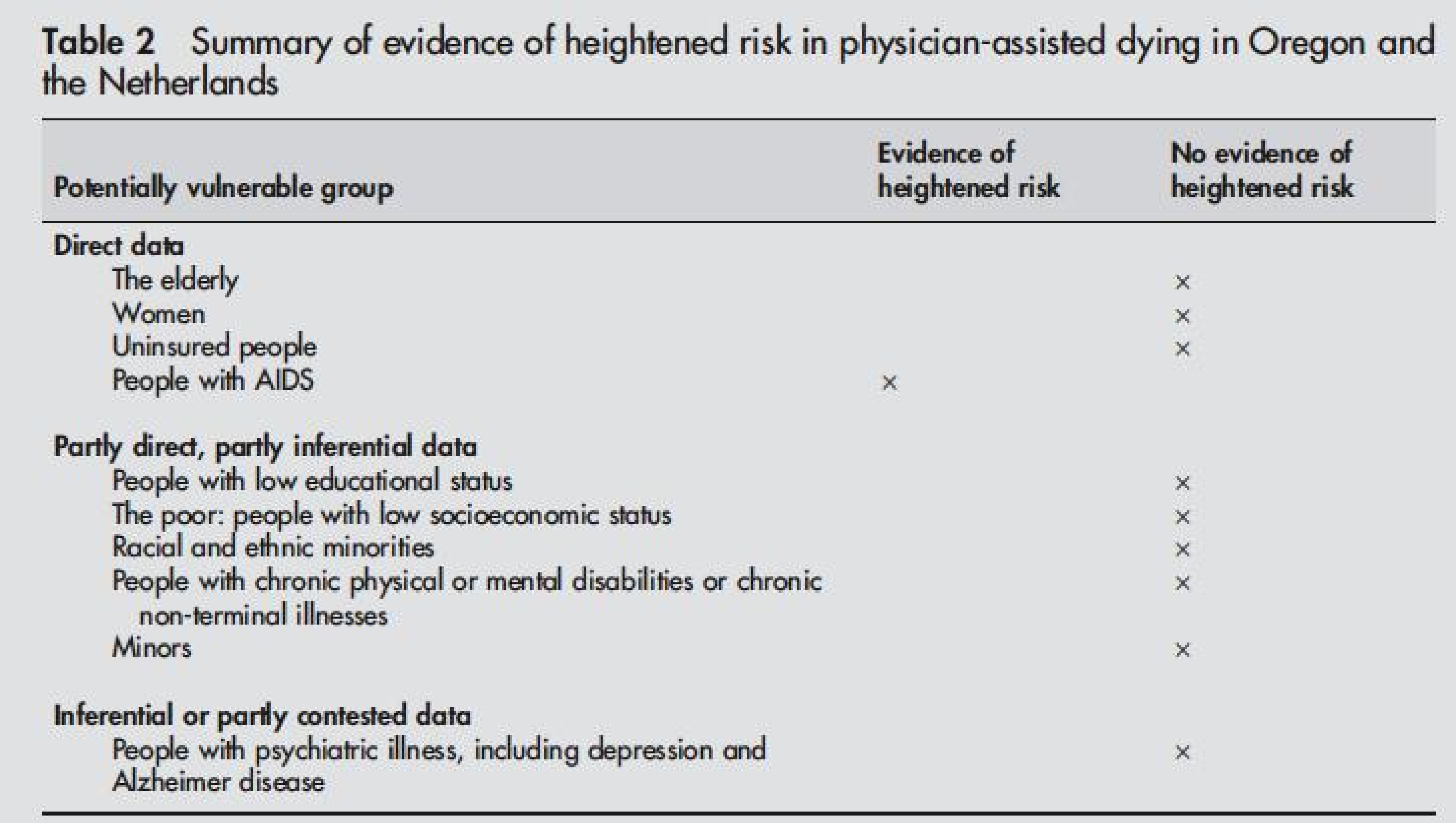

Table 2 Summary of evidence of heightened risk in physician-assisted dying in Oregon and the Netherlands

Potentially vulnerable group	Evidence of heightened risk	No evidence of heightened risk
Direct data		
The elderly		×
Women		×
Uninsured people		×
People with AIDS	×	
Partly direct, partly inferential data		
People with low educational status		×
The poor: people with low socioeconomic status		×
Racial and ethnic minorities		×
People with chronic physical or mental disabilities or chronic non-terminal illnesses		×
Minors		×
Inferential or partly contested data		
People with psychiatric illness, including depression and Alzheimer disease		×

J Med Ethics 2007;33:591–597.

Conclusions

- Requests for Hastened Death among terminally ill patients occur commonly

- WTHD is a reactive phenomenon, a response to a multidimensional suffering

- Comprehensive palliative care requires that careful attention be paid to the physical, psychosocial, existential and spiritual sources of end-of-life distress

To receive adequate control of symptoms and palliative care at the end of life is a **Human Right**.

Alfred Kubin, the “Austrian Goya”, THE BEST DOCTOR