

Relevance of Palliative Care and Hospice for Dialysis Patients

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Setting the Context

Mr. Higgins (not his real name) is a 67 year-old man who has been on CCPD for several years for ESRD from diabetic nephropathy. He had a massive heart attack and has an ejection fraction of only 10%. His CAD is not amenable to further revascularization interventions, and he has chronic CHF. Over the past two years he has had multiple hospitalizations. As a last resort, his nephrologist tried to persuade him to change to hemodialysis to see if he would do any better, but he and his wife insist on staying with PD. He is severally malnourished with a serum albumin of 2.0. Because of his heart disease and diabetic autonomic insufficiency, he occasionally becomes lightheaded on sitting and tolerates prolonged standing poorly.

Multiple interventions have been tried to improve his poor appetite and low energy level with no success. He is intermittently short of breath even at rest. Oxygen does not help. He has been offered exercise training, an ICD, and a chronic inotrope infusion, but he has declined these interventions. He wants to stay at home. His care is exhausting to his wife. He has stopped coming for monthly dialysis appointments because it is so difficult for him, and the nephrologist and PD nurse make home visits. The patient, his wife, and the nephrology team all know that the patient is slowly dying. He wants to die at home. He does not want to stop dialysis even though he knows his health is rapidly declining. What can be done to help Mr. Higgins and family?

Three Points

- Mr. Higgins' goals for care are different than those of most dialysis patients.
- Patient-centered care for him would look different than for another dialysis patient.
- There is an available approach to achieve his goals for treatment, but it is not widely used in dialysis facilities.

Objectives

1. Describe the growing relevance of palliative care to dialysis patients
2. Discuss the underutilization of hospice by dialysis patients and reasons for the low referral rate of dialysis patients to hospice
3. Explain how a palliative care approach can improve quality of life for dialysis patients
4. Identify the benefits of advance care planning for dialysis patients
5. Highlight the national Kidney End-of-Life Coalition as a resource for dialysis units

Palliative Care

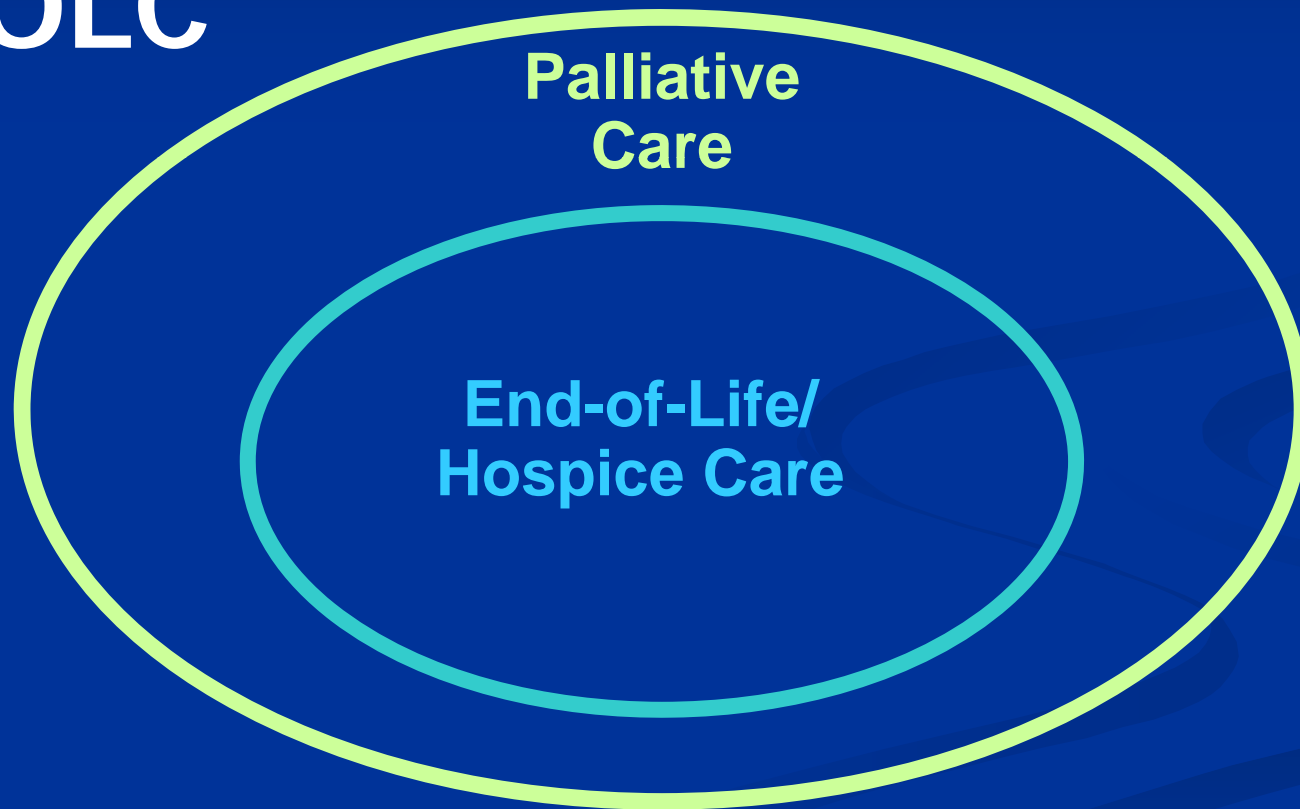
The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of their stage of disease or the need for other therapies, in accordance with their values and preferences.

Morrison RS, Meier DE. Palliative care.
N Engl J Med 2004;350:2582-90.

Elements of Palliative Care

- Meticulous pain and symptom assessment and control
- Psychosocial and spiritual support to patient/family
- Goal clarification including advance care planning
- Family-oriented care
- Delivery of coordinated services
- Attention to disposition to setting desired by patient

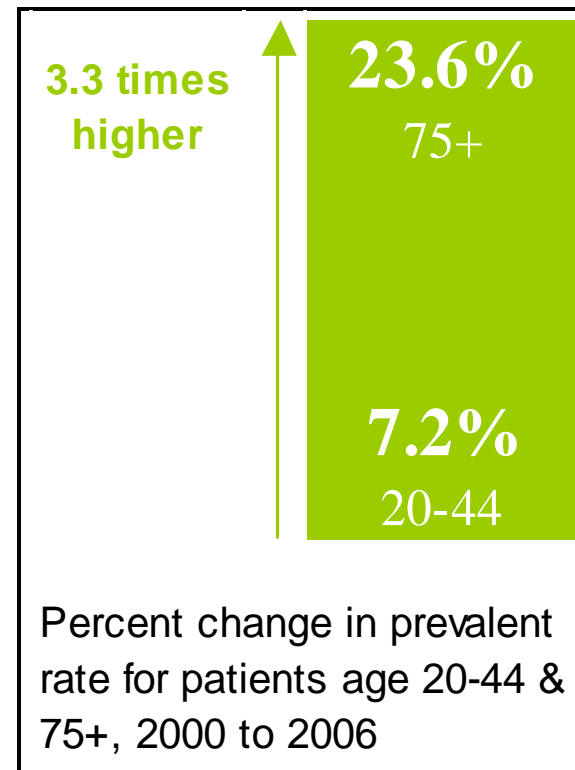
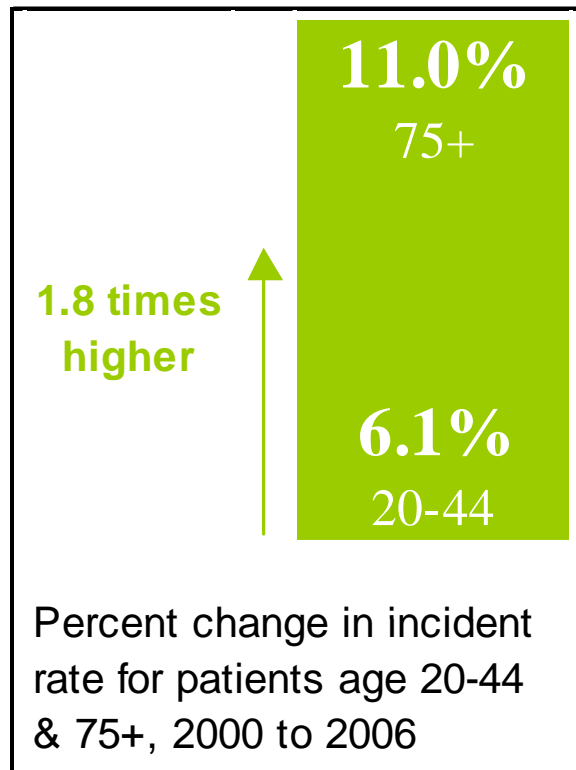
Relationship between Palliative Care and EOLC



Palliative Care: Relevance to ESRD

- Aging Population
- Shortened life expectancy
- Multiple comorbidities
- High symptom burden
- Nephrologists not prepared in training

Percent change in rate by patient age



Withdrawal and Hospice Status by Age

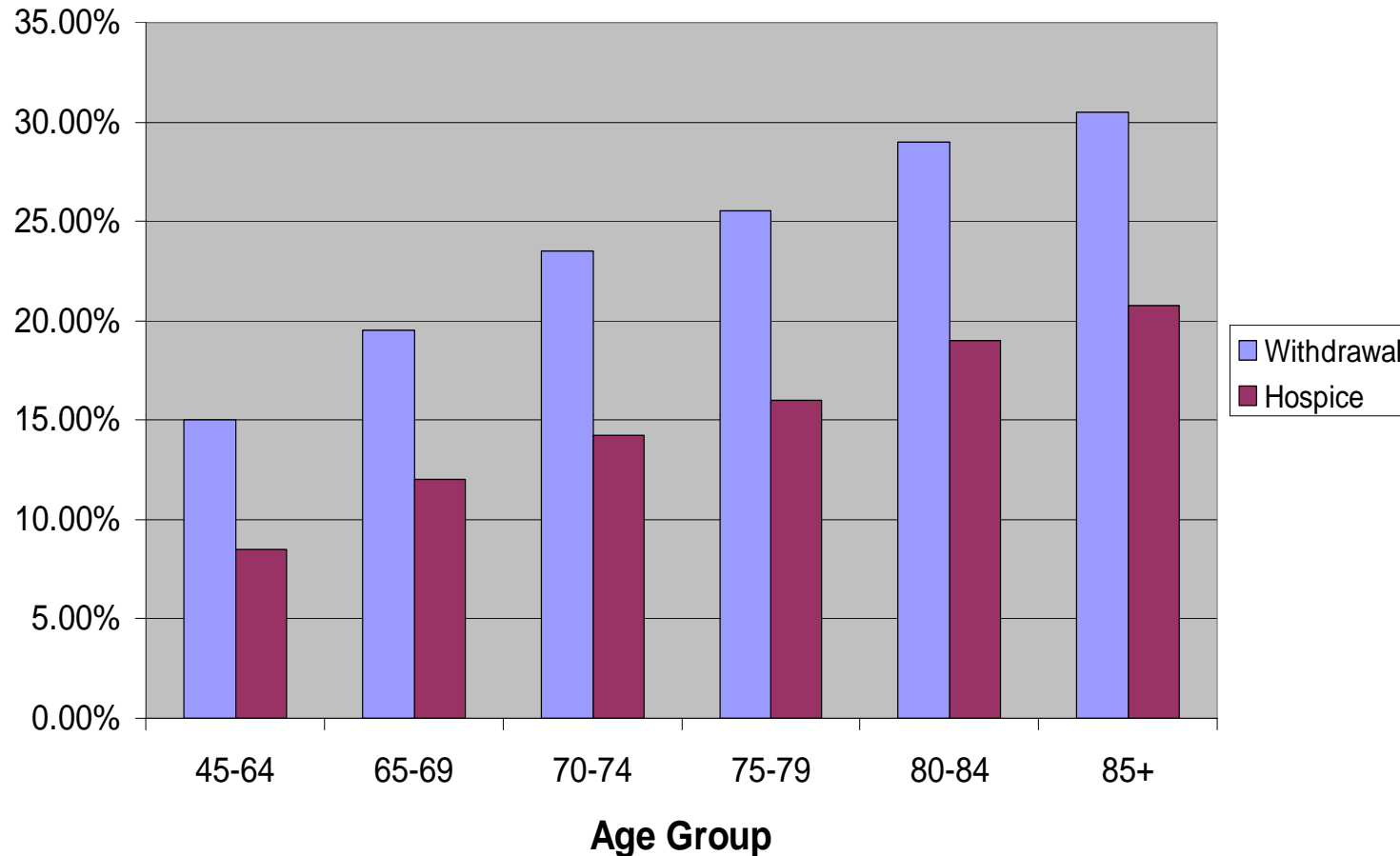


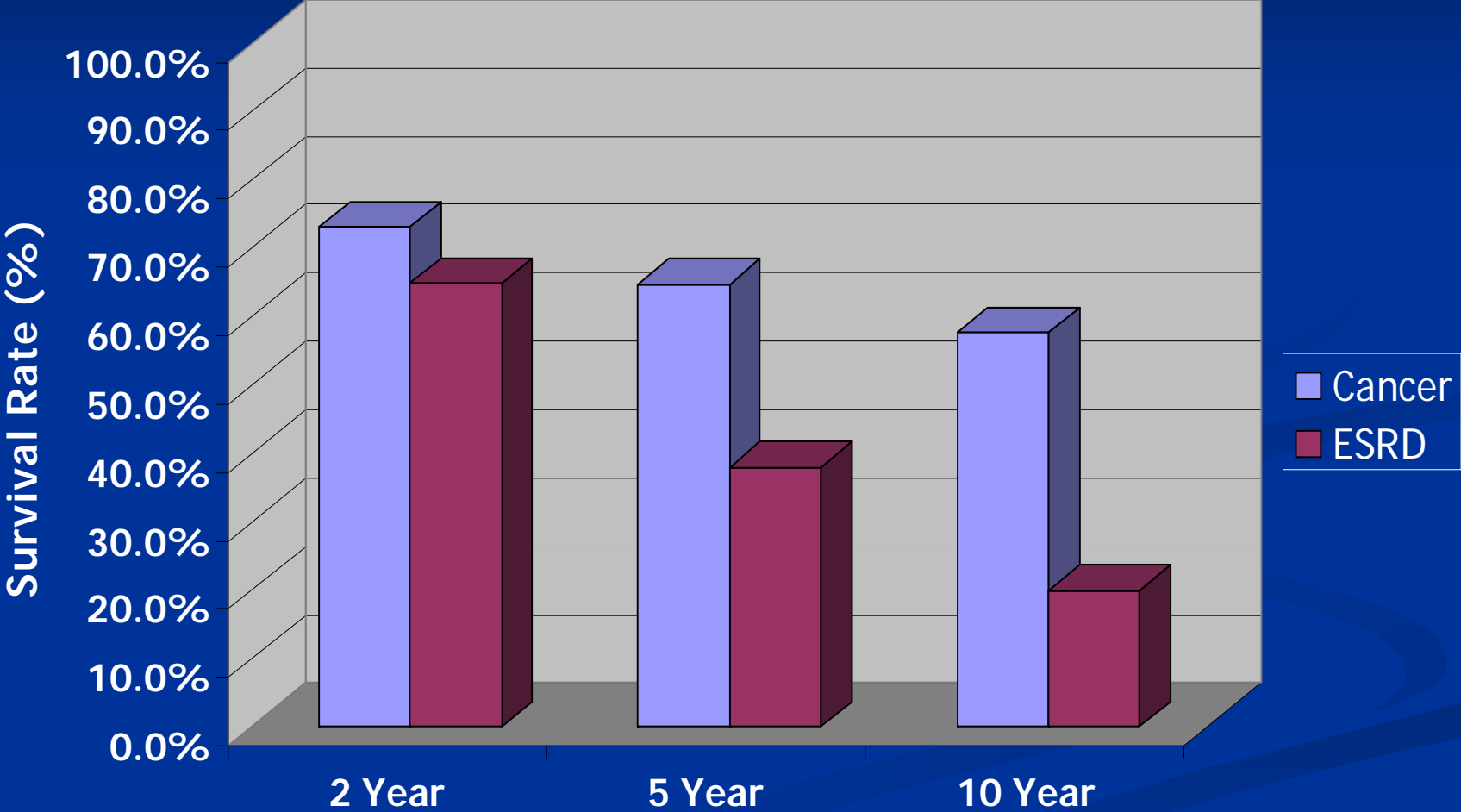
Figure 1. Dialysis withdrawal and hospice status by age, US Renal Data System (USRDS) 2001 to 2002 deceased cohort (N = 115,239).

Murray et al. Use of Hospice in the United States Dialysis Population. *Clinical J Am Soc Nephrol.* 2006;1:1248-1255.

Expected Remaining Years of Life For 2006 Dialysis Populations- USRDS

Age	US Gen Pop	Black	Dialysis	% as Long
20-24	56.9	52.7	14.5	25.5
30-34	47.4	43.5	11.1	23.4
40-44	38.0	34.5	8.3	21.8
50-54	29.2	26.3	6.3	21.6
60-64	21.0	19.1	4.6	21.9
70-74	13.8	13.0	3.3	23.9
85+	4.4	5.0	1.9	43.2

Survival Rates for Cancer and ESRD Patients

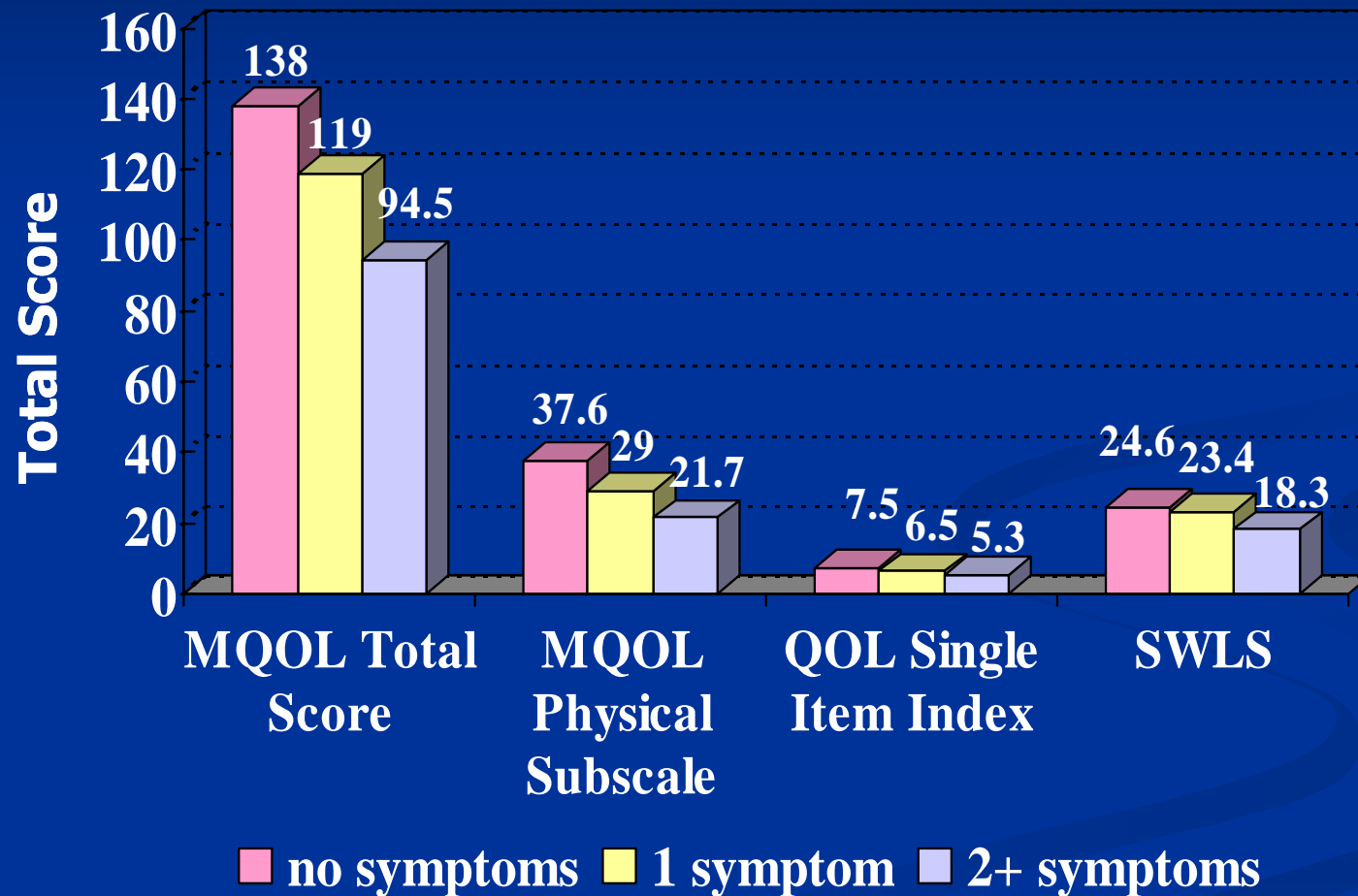


Data from USRDS and NCI

High Symptom Burden

- HD patients median # of symptoms=9
- Pain in over 50%
- Associated with impaired HRQoL
- Associated with depression

Association Between Symptoms and Quality of Life Measures



Note:
All results
statistically
significant,
p values <.01

Predictors of Poor Prognosis for ESRD Patients

- ❑ Age
- ❑ Functional ability
- ❑ Nutritional status
- ❑ Comorbid Illnesses—eg, DM, MI, CHF

RPA/ASN. Shared Decision-Making in the Appropriate
Initiation of and Withdrawal from Dialysis. 2000.

The “Surprise” Question:

A Trigger

for Palliative Care Evaluation and
Advance Care Planning

“Would I be surprised if this
patient died in the next year?”

Moss A., et. al. Utility of the “Surprise” Question to Identify Dialysis Patients
with High Mortality. *Clin J Am Soc Nephrol* 2008;3:1379-1384

Initial Demographics, Quality of Life, and Prognostic Factor Scores*

Variable	All (N=150)	Yes (N=115)	No (N=35)	P value
Age (yrs)	66.6±15.83	64.3±15.4	74.1±12.6	0.002
Serum Albumin	3.9±0.3	3.9±0.29	3.7±0.41	0.01
Pain Score	2.6±3.2	2.6±3.3	2.3±2.9	0.601
McGill Quality of Life question	6.7±2.1	6.8±2.1	6.5±2.0	0.518
Charlson Comorbidity Score	6.0±2.2	5.8±2.1	7.0±2.3	0.003
Karnofsky Performance Status	78.7±17.1	81.6±15.9	68.7±17.7	0.001

*Values are mean ± SD. "Yes" indicates patients in the "Yes, I would be surprised" group. "No" indicates the "No, I would not be surprised" group.

Table 2. Univariate logistic regression analysis to predict status at 12 months

Predictor	OR (95% CI)	P
"Surprise" Question Response (reference = "Yes")	3.507 (1.356 to 9.067)	0.01
CCI Score	1.417 (1.099 to 1.826)	0.007
Karnofsky Performance Status Score	0.964 (0.937 to 0.992)	0.012
Quality of Life Score	0.859 (0.693 to 1.065)	0.166
Visual Analogue Scale	1.109 (0.962 to 1.279)	0.153
Serum Albumin	0.329 (0.080 to 1.350)	0.123
Mean Kt/V	1.242 (0.238 to 6.489)	0.797
Serum Hb	1.084 (0.692 to 1.699)	0.724
Gender	0.974 (0.392 to 2.420)	0.955
Race	0.324 (0.041 to 2.580)	0.287
Time on Dialysis (months)	1.006 (0.995 to 1.016)	0.293
Age	1.012 (0.980 to 1.045)	0.469

OR indicates odds ratio. For those for whom the "surprise" question was answered "No," the odds of dying within a year were 3.507 times the odds of dying for those for whom the "surprise" question response was "Yes." CCI indicates Charlson Comorbidity Index. Kt/V indicates the dialysis index. Hb indicates serum hemoglobin.

Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis

Lewis M. Cohen,* Robin Ruthazer,[†] Alvin H. Moss,[‡] and Michael J. Germain[§]

Results: In a Cox multivariate analysis of the derivation cohort (N=449), five variables were independently associated with early mortality: Older **age** (hazard ratio [HR] for a 10-yr increase 1.35; 95% confidence interval [CI] 1.17 to 1.57), **dementia** (HR 1.88; 95% CI 1.24 to 2.84), **peripheral vascular disease** (HR 2.24; 95% CI 1.11 to 4.48), **decreased albumin** (HR for a 1-U increase 0.27; 95% CI 0.15 to 0.50), and **SQ** (HR 2.71; 95% CI 1.76 to 4.17). Area under the curve for the resulting prognostic model predictions of 6-mo mortality were 0.87 (95% CI 0.82 to 0.92) in the derivation cohort and 0.80 (95% CI 0.73 to 0.88) in the validation cohort.

Conclusions: An integrated 6-mo prognostic tool was developed and validated for the HD population. The instrument may be of value for researchers and clinicians to improve end-of-life care by providing more accurate prognostic information.

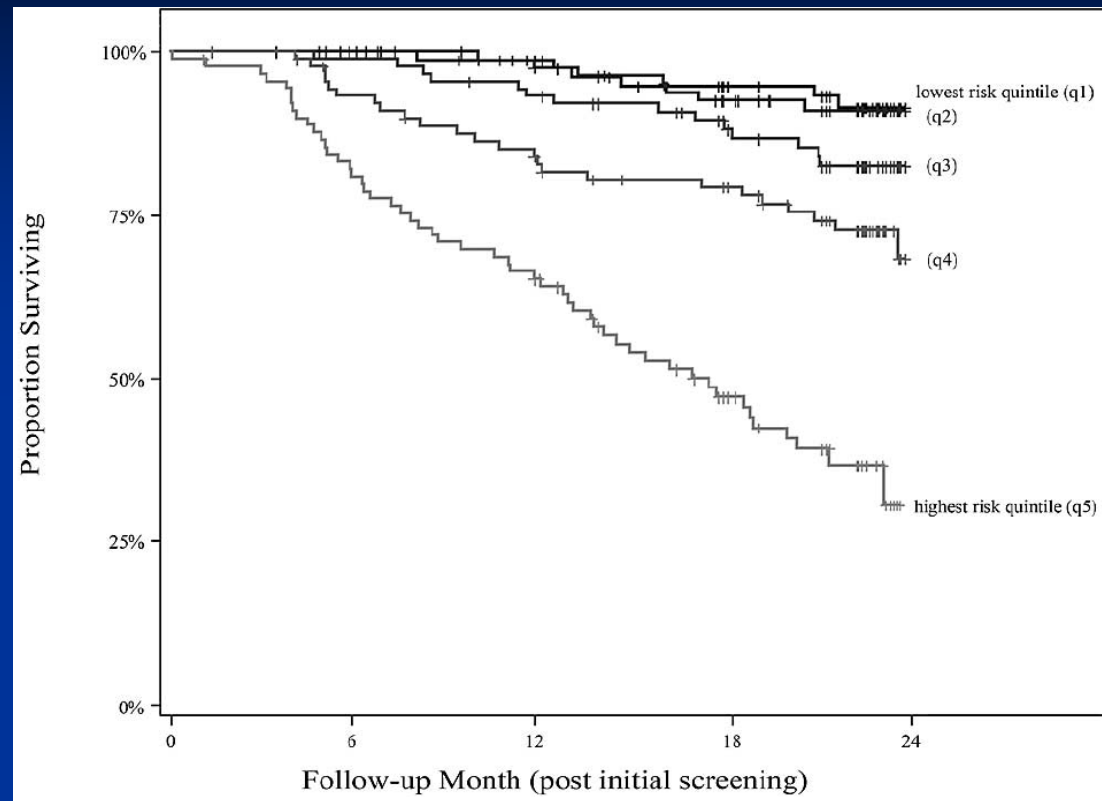
Table 3. Multivariable model of survival in the derivation cohort (n = 449 patients with complete data, 103 died)

Variable ^a	HR	95% CI
SQ, not surprised <i>versus</i> surprised	2.71	1.75 to 4.17
Albumin (HR expressed for a 1-U increase)	0.27	0.15 to 0.50
Age (yr; HR expressed for a 10-yr increase)	1.36	1.17 to 1.57
PVD, yes <i>versus</i> no	1.88	1.24 to 2.84
Dementia, yes <i>versus</i> no	2.24	1.11 to 4.48

^aThe age range for model development was 16 to 92; albumin range was 1.7 to 5.0. This model should not be applied to cases with ages or albumin values beyond these ranges. Albumin values <3.0 were recoded to 3.0 and values >4.5 were recoded to 4.5 for the model derivation.

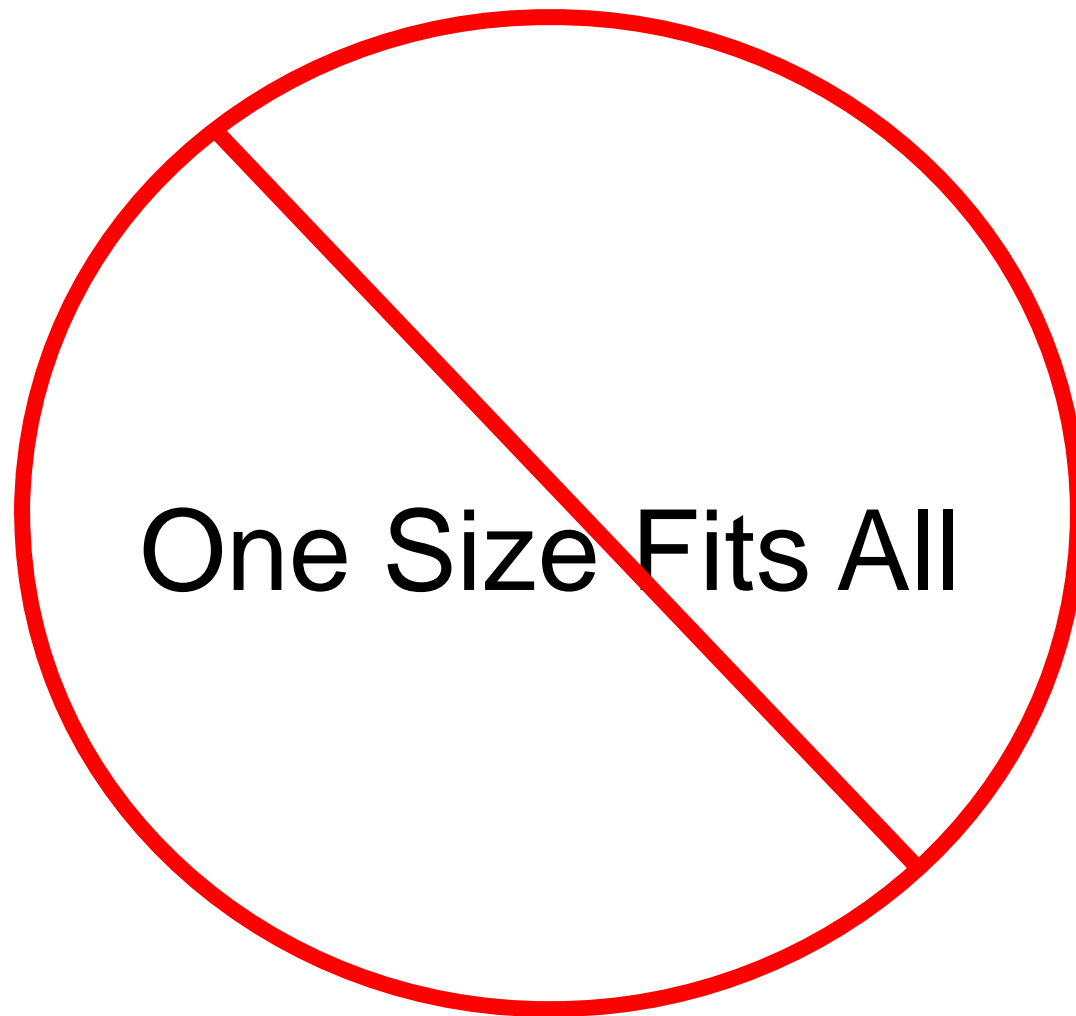
Cohen LM, Ruthazer R, Moss AH, Germain MJ. Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis. *CJASN* 2010; 5:72-79.

Figure 2. Survival across quintiles of predicted risk



The model successfully predicted which patients had worse and better survival over time with patients in quintile 5- the highest risk quartile- having the poorest survival ($P < 0.001$).

Cohen LM, Ruthazer R, Moss AH, Germain MJ. Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis. *CJASN* 2010;5:72-79.



There are clinically discernable differences in dialysis patients; not all have the same goals for their treatment. Remember Mr. Higgins!

Quality Care

“The right care
for the right patient
at the right time.”

Carolyn Clancy, MD
Director, Agency for Healthcare Quality and Research

CPMs for Quality Care for Dying Dialysis Patients

- Estimate of prognosis
- Patient designation of healthcare agent
- Completion of an end-of-life care plan
 - Preferences regarding life-sustaining treatments
 - Preferred site of death
- Pain and symptom assessment and management
- Timely referral to hospice

Hospice Use by Dialysis Patients

Medicare Benefit Policy Manual

Chapter 11 - End Stage Renal Disease (ESRD)

Table of Contents

(Rev. 27, Issued: 11-23-04)

50.6.1.4 – Coverage Under the Hospice Benefit

(Rev. 1, 10-01-03)

If the patient's terminal condition is not related to ESRD, the patient may receive covered services under both the ESRD benefit and the hospice benefit. A patient does not need to stop dialysis treatment to receive care under the hospice benefit. Consequently, hospice agencies can provide hospice services to patients who wish to continue dialysis treatment.

Death After Dialysis Withdrawal: Are Patients Appropriate for Hospice?

Study	Year	N	Mean	Range
Neu & Kjellstrand	1986	155	8.1 days	1 - 29
Sekkarie & Moss	1998	60	12 days	0 - 150
Cohen et al	2000	126	8.2 days	1 - 46

96% are dead within 1 mo of stopping dialysis.

Dialysis Withdrawal and Hospice Status of Deceased Patients USRDS 2001-2002 Cohort

Dialysis Withdrawal and Hospice Status	Deceased Patients (N=115,239)	Percent	Mean Age in Years
Hospice Yes	15,565	13.5	73.4 ± 11.0 *
Hospice No	99,674	86.5	68.6 ± 13.4
Withdrawal Yes	25,075	21.8	72.7 ± 11.8 **
Hospice Yes	10,518	41.9	73.9 ± 10.6
Hospice No	14,557	58.1	71.7 ± 12.3
Withdrawal No	81,624	70.8	68.0 ± 13.4
Hospice Yes	2,751	3.4	71.7 ± 11.7
Hospice No	78,873	96.6	67.9 ± 13.5
Withdrawal Status Unknown	8,540	7.4	71.1 ± 13.2

Murray et al. Use of Hospice in the United States Dialysis Population.
Clinical J Am Soc Nephrol. 2006;1:1248-1255.

Deceased Patients 2001-2002

	Number of patients	Mean cost* last 6 mths of life-dollars	Mean cost* last week of life	Mean hospital days last week
6 month cohort	91,687	64,461	6,885	3.0
Patients who withdrew	19,517	63,735	5,024	2.8
Withdrew & used hospice	8,200	60,261	3,324	1.4
Withdrew & did not use hospice	11,317	66,253	6,257	3.7
Hospice no withdrawal	2,165	64,979	4,318	1.8
No withdrawal	65,868	65,345	7,588	3.1

Site of Death & Hospice Days

	Site of Death	Site of death %	Mean days in hospice
6 month cohort N=91,687	Hospital	63.0	2.0
	Home	16.7	
	Other	11.1	
	Unknown	8.4	
Patients who withdrew	Hospital	49.2	4.4
	Home	25.3	
Withdrew & used hospice	Hospital	22.5	10.1
	Home	45.3	
Withdrew & did not use hospice	Hospital	68.5	0
	Home	10.8	
Hospice no withdrawal	Hospital	41.8	21.0
	Home	37.3	

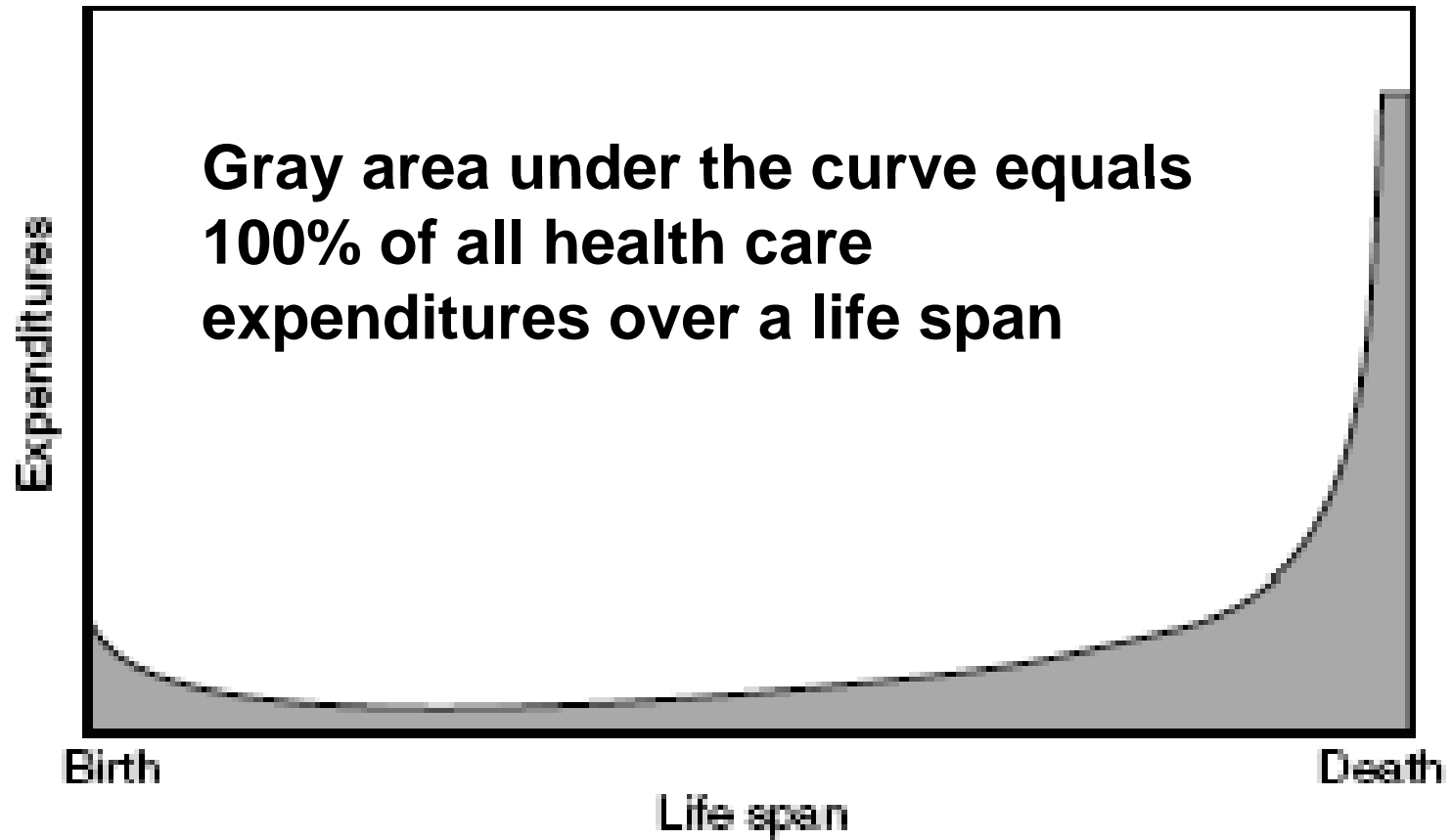


Figure 1. Americans' Current Health Care Expenditures Are Concentrated in the Final Part of the Life Span

Updated Dialysis Statistics

2007 Dialysis Deaths

Patients	Number (%)	Number (%) Using Hospice
Stopped Dialysis	19,312 (24)	11,814 (61)
Continued Dialysis	60,173 (76)	3,152 (5)
Total	79,485 (100)	14,966 (19)

Source: Network/SIMS Data from CMS 2746 assembled by MARC under contract #HHSM-500-2006-NW005C

Knowledge of Patient's Eligibility to Receive Dual Benefits with a Terminal Illness Unrelated to Kidney Disease by Discipline

Discipline	Can Receive Dual Benefits	Cannot Receive Dual Benefits	No Answer	Total Interviewed	P value
Social Workers # (%)	91 (79)	7 (6)	17 (15)	115	<.001
Nurse Managers # (%)	105 (64)	18 (11)	41 (25)	164	
Registered Nurses # (%)	28 (48)	12 (20)	19 (32)	59	

Respondents who correctly understood the Medicare hospice benefit for dialysis patients indicated that dialysis patients are eligible to receive both the Medicare ESRD benefit and the Medicare hospice benefit at the same time if the dialysis patient's terminal illness is unrelated to kidney disease.

Uncertainty of Hospice Referral Process by Discipline

Discipline	Uncertain of Hospice Referral Process	Other Reason for Hospice Non-referral	Total	P value
Social Workers # (%)	10 (9)	105 (91)	115	<.001
Nurse Managers # (%)	46 (28)	118 (72)	164	
Registered Nurses # (%)	10 (17)	49 (83)	59	

In response to the question, “If the patient was not referred to hospice, the reasons for lack of referral include,” respondents were identified who selected “uncertain about the referral process.”

Acceptance of Hospice Referral by Race and Region

ESRD Network	White	Black	Total
*NW1 # (%)	43 (73) **	4 (80)	47 (73)
NW5 # (%)	29 (74)	26 (79)	55 (76)
NW12 # (%)	47 (81)	9 (69)	56 (79)
Total	119 (76)	39 (77)	158 (76)

*NW indicates ESRD Network. **The numbers represent the number who accepted referral to hospice per ESRD Network and the percentage of the number of patients by race who were referred to hospice. There was no difference in the number of patients who accepted hospice by ESRD Network (P=0.99). There was no difference in the number of patients who accepted hospice by race (P=0.99). There was no significant interaction between ESRD Network and race (P=.56).

Pain and ESRD

- A common and severe symptom
- Impairs quality of life
- **Undertreated in 75% of ESRD patients***
- Lack of knowledge in nephrology community

*Davison SN. *Am J Kidney Dis*, 42:1239-1247, 2003

*Barakzoy & Moss. *J Am Soc Nephrol*. 2006;17:3198-3203

*Bailie GR, et al. *Kidney Int* 2004;65:2419-2425

Causes of Pain in Hemodialysis Patients

N=103/205*

Cause	# Patients	Percent
Musculoskeletal	65	63
Osteoarthritis	20	19
Skeletal s Dx	19	19
Osteoporosis	12	12
RA, Bone Dis, Osteo	14	14
Related to dialysis	14	14
Peripheral Neuropathy	13	13
Periph Vasc Disease	10	10
Carpal tunnel	2	2
Other	19	19

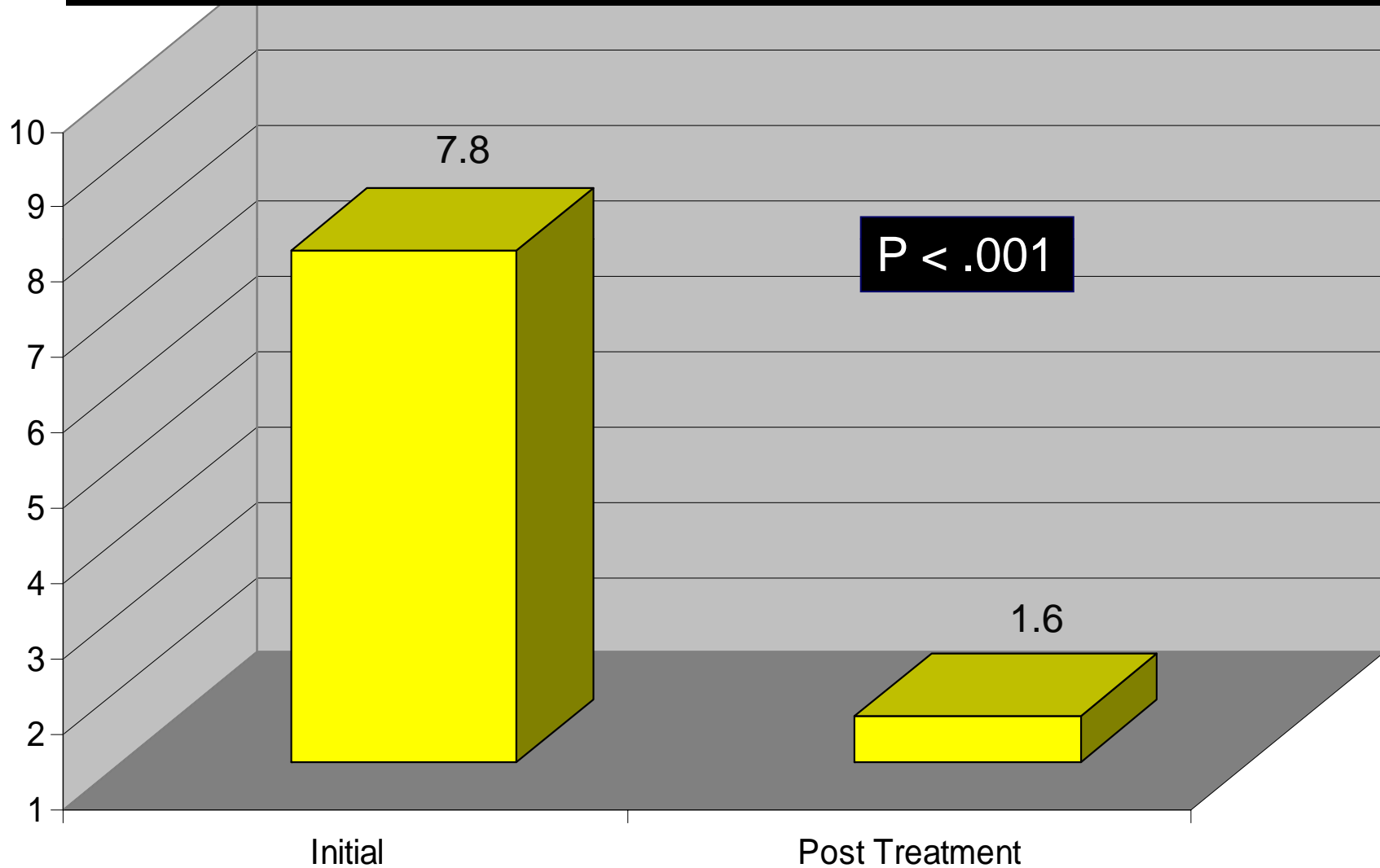
* 19 > one type of pain.

Davison, *AJKD* 2003;42:1239-1247

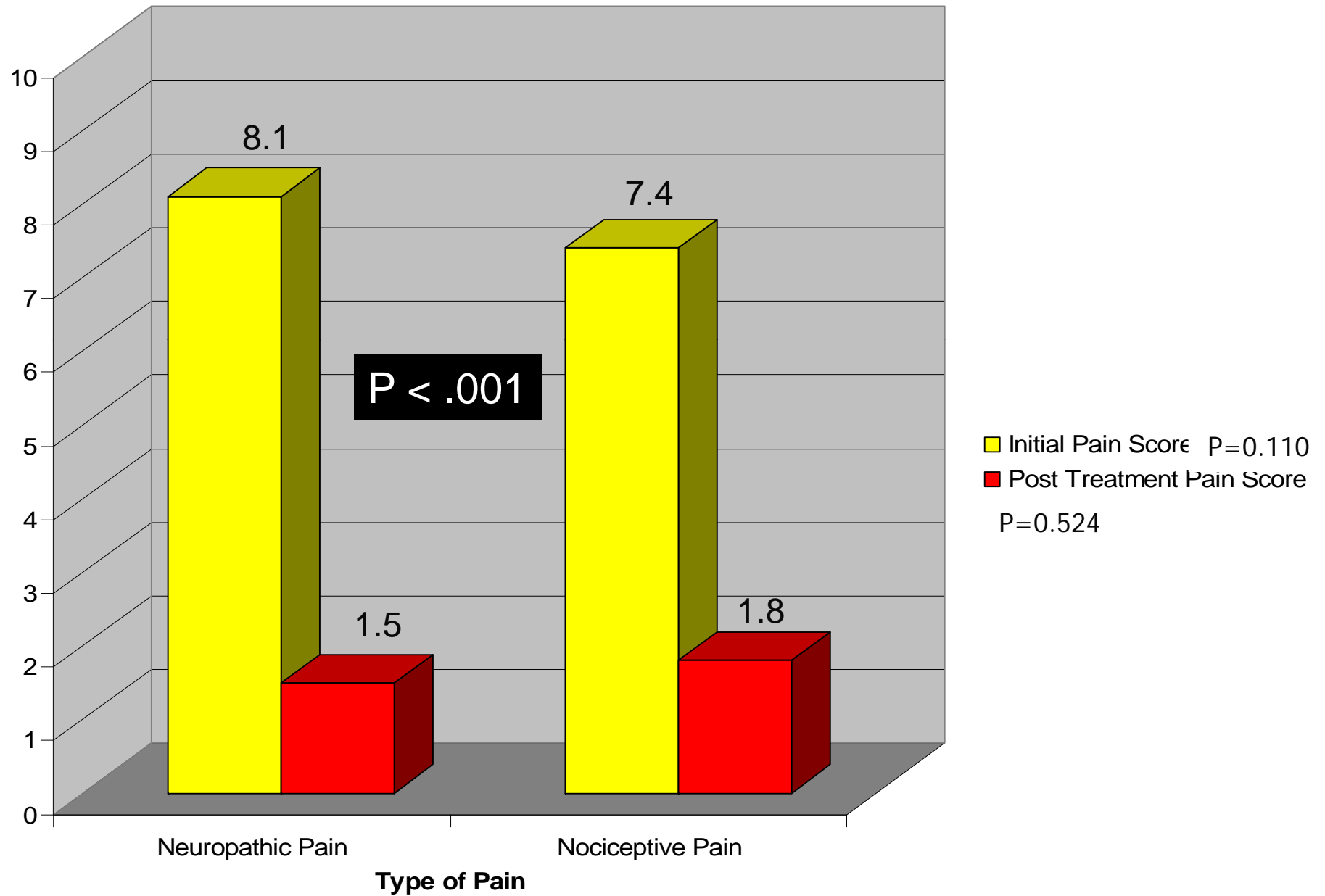
Comparison of Initial and Post Treatment Mean Pain Scores

n = 45

Barakzoy and Moss. *J Am Soc Nephrol.* 2006;17:3198-3203.



Comparison of Initial and Post-Treatment Pain Scores



Incorporating Palliative Care into the Dialysis Unit

- “Surprise” question on rounds
- Educational in-services on palliative care topics
- Pain & symptom assessment and treatment protocols
- Advance care planning
- Communication of prognosis and changes in condition
- Palliative care consultation
- Referral to hospice when terminally ill
- QI with review of quality of death
- Memorial service

Conditions for Coverage

Subpart C—Patient Care

(a) *Standard: Patients' rights.* The patient has the right to...

- (1) Respect, dignity, and recognition of his or her individuality and personal needs, and sensitivity to his or her psychological needs and ability to cope with ESRD; ...
- (5) Be informed about and participate, if desired, in all aspects of his or her care, and be informed of the right to refuse treatment, to discontinue treatment, and to refuse to participate in experimental research;
- (6) **Be informed about his or her right to execute advance directives, and the facility's policy regarding advance directives...**

Definition of Advance Care Planning

“ACP is a *process* that involves understanding, reflection, communication, and discussion between a patient, family/health care proxy, and staff for the purpose of prospectively

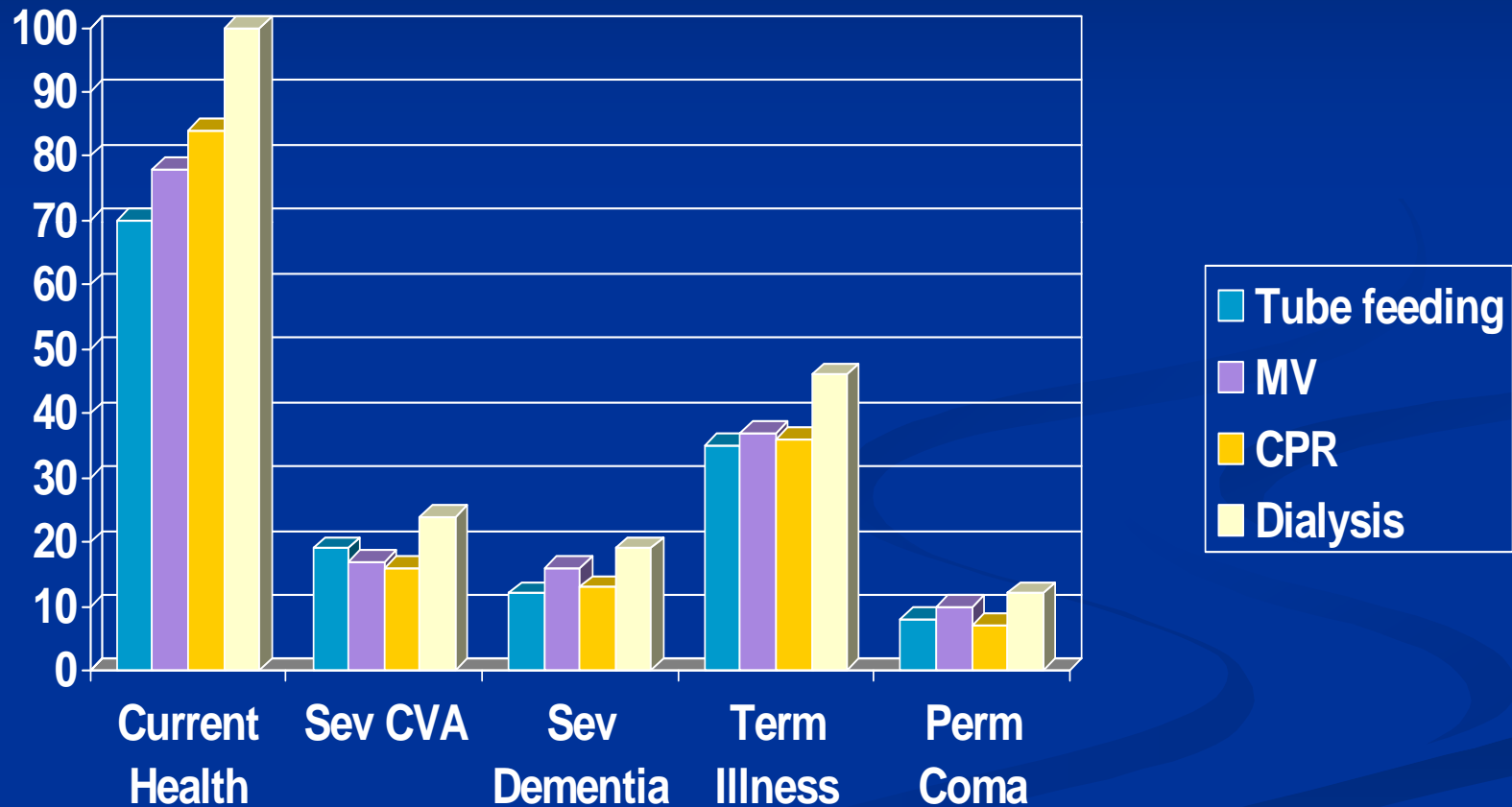
- 1) identifying a surrogate (health care proxy),
- 2) clarifying preferences, and
- 3) developing individualized plans for care near the end of life.”

Goals of Care and ACP

“Goals of care are inextricably linked with patient and family understanding of illness and expectations. In the context of facilitated ACP, it is clear that goals must reflect expectations that are in balance with adequate knowledge.”

Davison, et. al. *Am J Kidney Dis* 2007;49: 27-36.

Patients' Desires for Treatments in Various Health States (%)



Singer, et al. *J Am Soc Nephrol* 1995;6:1410-1417

What did we do for Mr. Higgins?

1. Identified goals of care
2. Completed a living will/medical power of attorney
3. Completed a Physician Orders for Scope of Treatment (POST) form
4. Started hydromorphone for SOB
5. Referred to hospice with terminal diagnosis of end-stage heart disease

KIDNEY END-OF-LIFE COALITION



For additional information, including resources for patients and families, visit www.kidneyeol.org

- Advance care planning information
- Do not resuscitate orders in the dialysis unit
- Access to hospice
- Clinician educational resources

Contact the Kidney End of Life Coalition at
kidneyeol@nw5.esrd.net

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis



rpa@renalmd.org
301.468.3515

Conclusions

- The changing demographics of the dialysis population portends a significantly increased need for palliative care.
- Dialysis patients underutilize hospice, and there are major opportunities to increase access to hospice for dialysis patients with cost savings.
- CMS and Networks should encourage dialysis units to incorporate palliative care and collaborate with hospices to improve the quality of life of dialysis patients at the end of life.
- Hospices should work with local dialysis facilities to improve end-of-life care for dialysis patients.
- Performance measures for dialysis patients appropriate for palliative care should be different to be patient-centered and accommodate patients' goals for care.
- The Kidney End-of-Life Coalition is a resource for dialysis units to improve dialysis patient care.

Future Conferences

February 17, 2010 12-1pm
Pain Assessment and Management
Sara Davison, MD

March 24, 2010 12-1pm
Symptom Assessment and Management
Steven Weisbord, MD

April 28, 2010 12-1pm
Incorporating Palliative Care into the Dialysis Unit
Michael Germain, MD

To Register Contact -

Samantha Dorr

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