

End of Life and Palliative care in Nephrology

**The need to come
together**

Outline

- ESRD Epidemiology
- Illustrative cases
- Renal Palliative and EOL Care
- Issues and challenges

Objectives

At the completion of this talk, participants should be able to:

- ❑ Explain why end-of-life care is especially appropriate for dialysis patients;
- ❑ Define palliative care and its role for dialysis patients;
- ❑ Have an awareness of the elements of EOL care for ESRD patients and dialysis programs

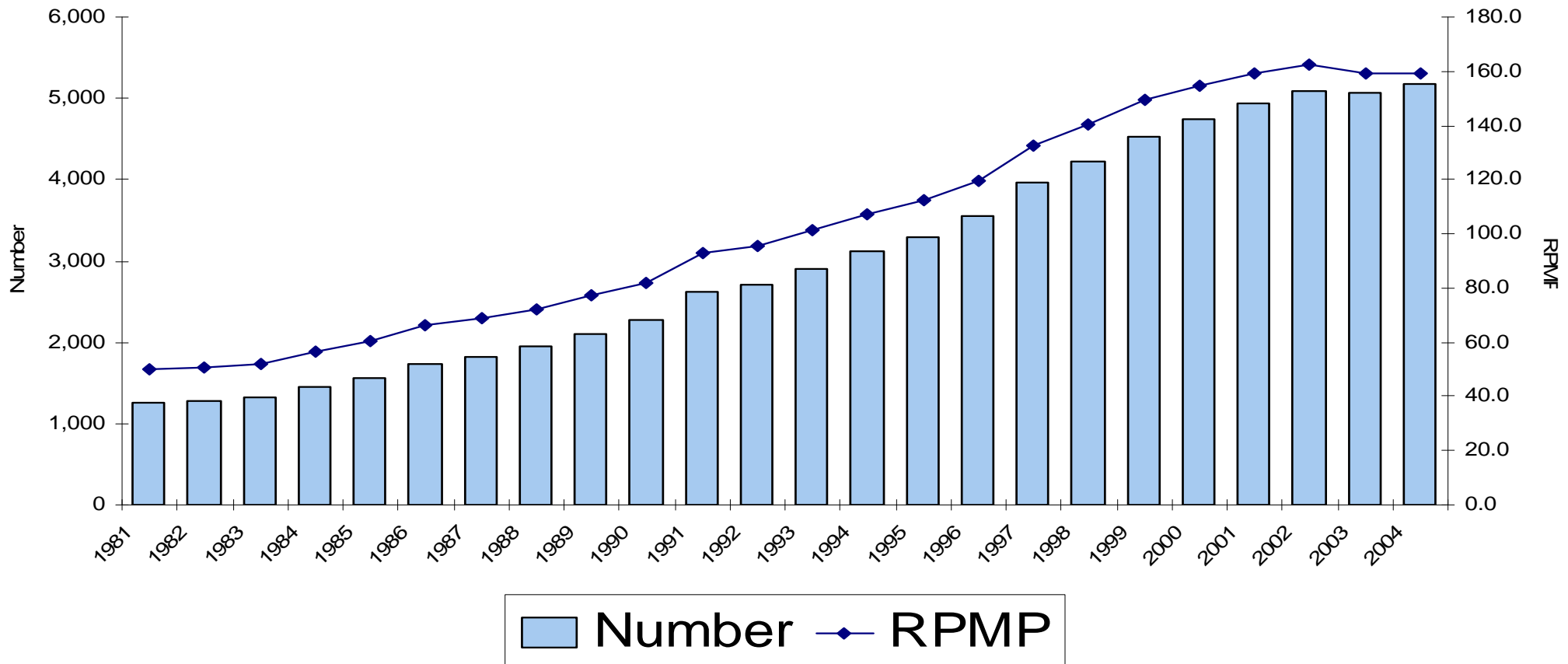
Renal Replacement Therapy Facilities in Canada, 2006

- 91 Dialysis Programs
- 27 Kidney Transplant Programs
- 130 Satellites Centres
- 14 Independent Health Facilities



ESRD Patients Starting Renal Replacement Therapy (RRT) in Canada, 1981-2004*

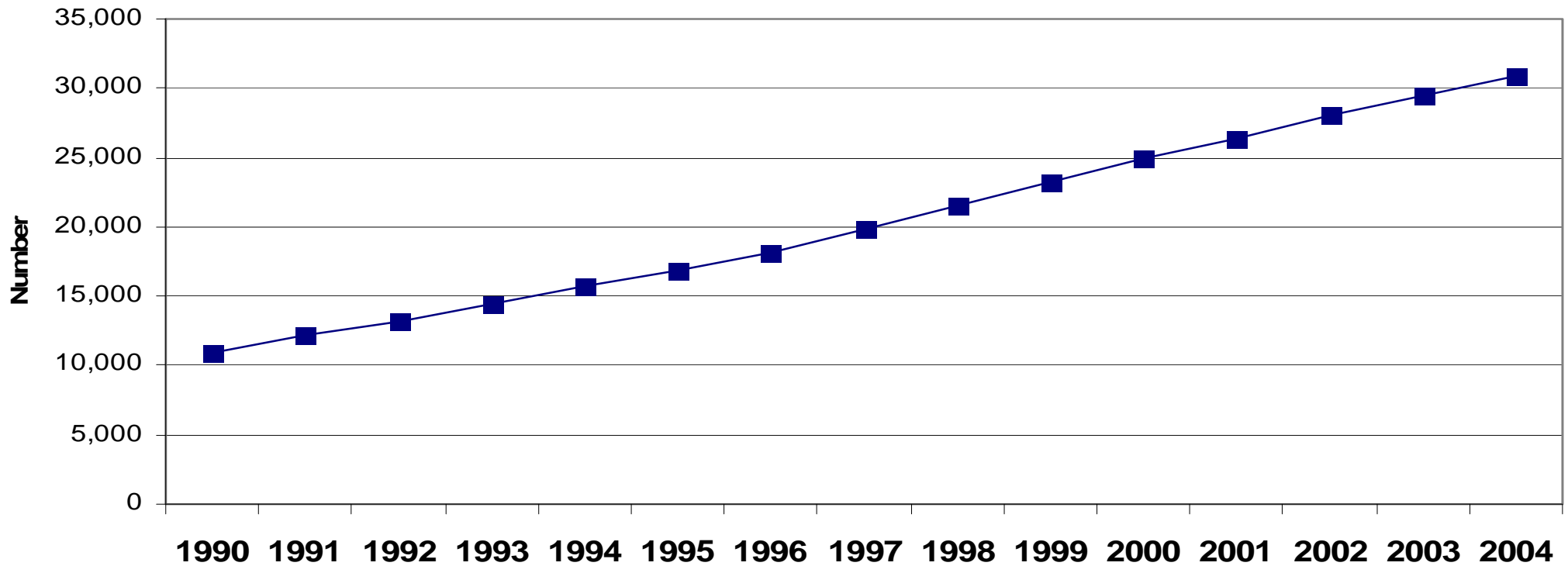
2004 N=5,178



Based on the patient level data . Data from Ontario, Alberta and Manitoba could be underreported

Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2006)

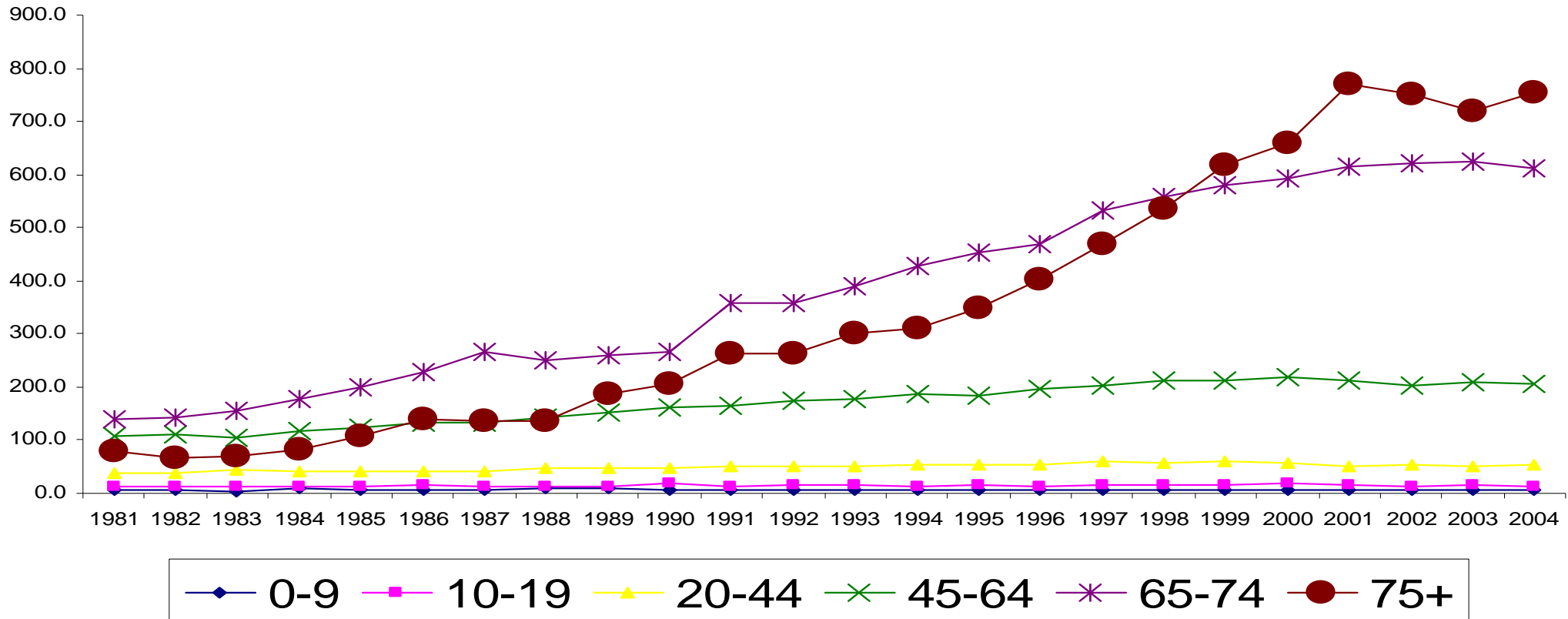
Prevalent ESRD Patients at Year-end, Canada, 1990-2004* (Number)



*Based on patient level data reported to the registry.

Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2006)

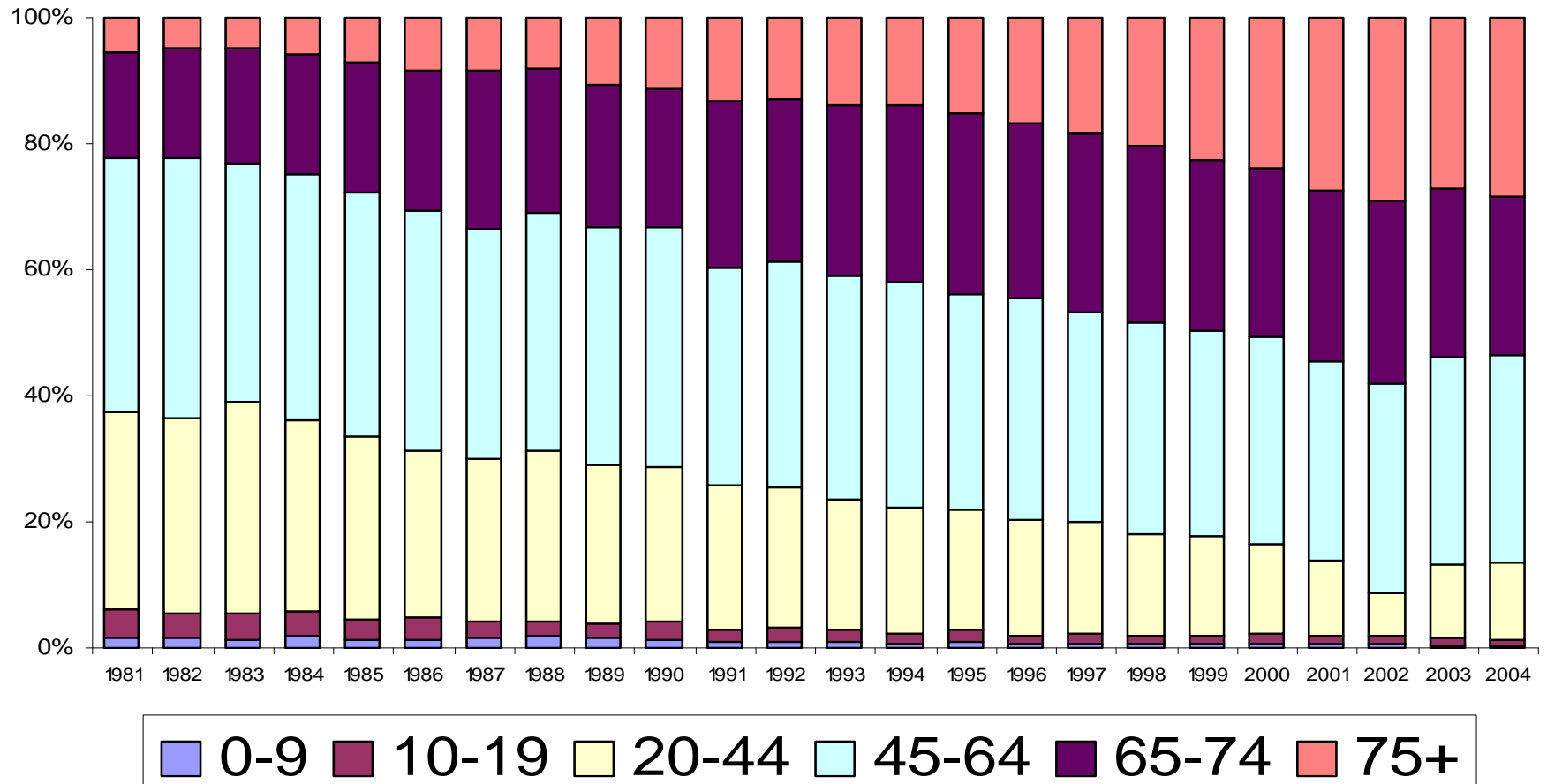
Incident ESRD Patients by Age Group, Canada, 1981-2004* (Age-specific Rates Per Million Population)



*Data are used from Patient Data Base Collected at the CORR. Minor adjustments made for the Manitoba data in 2004. 2004 data still might be influenced by some underreporting.

Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2006)

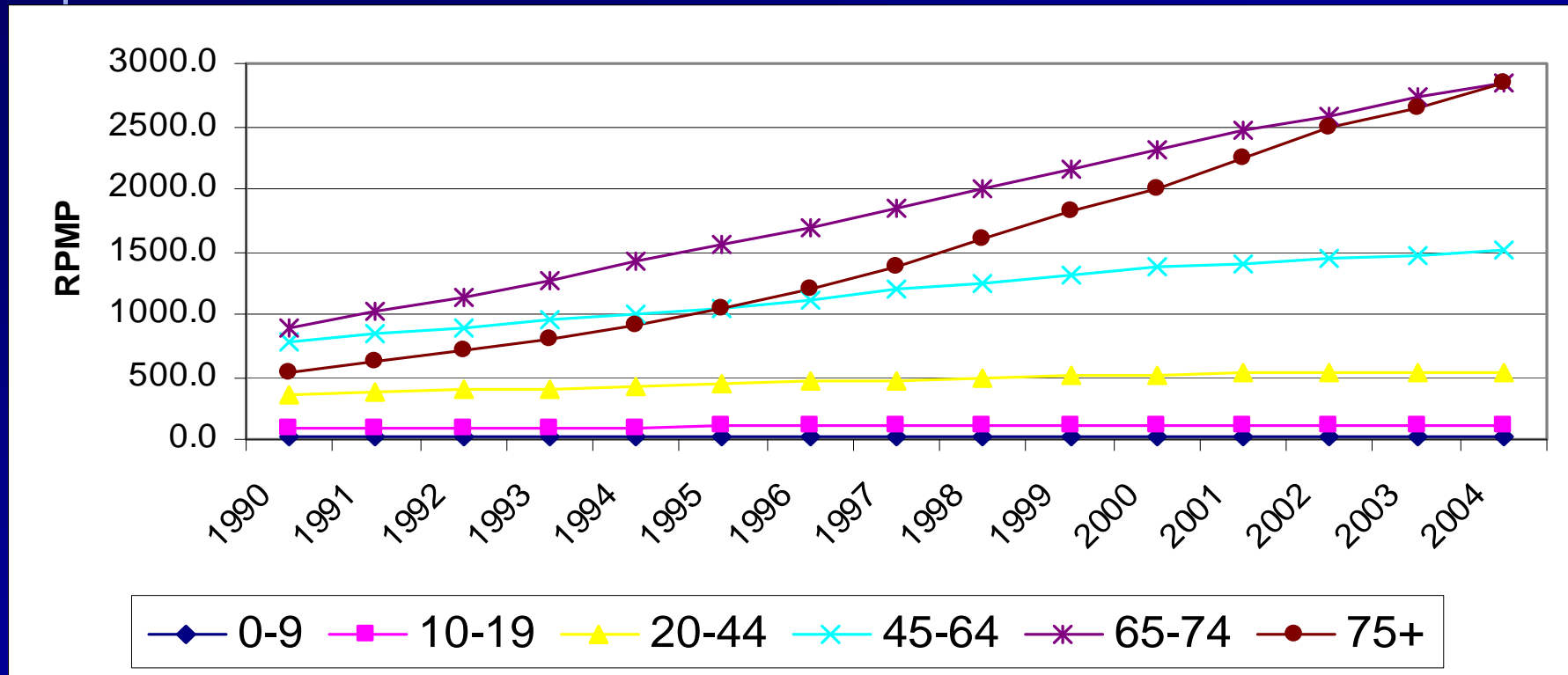
Distribution of Incident ESRD Patients by Age Group, Canada, 1981-2004*



*Data are used from Patient Data Base Collected at the CORR. Minor adjustments made for the Manitoba data in 2004. 2004 data still might be influenced by some underreporting.

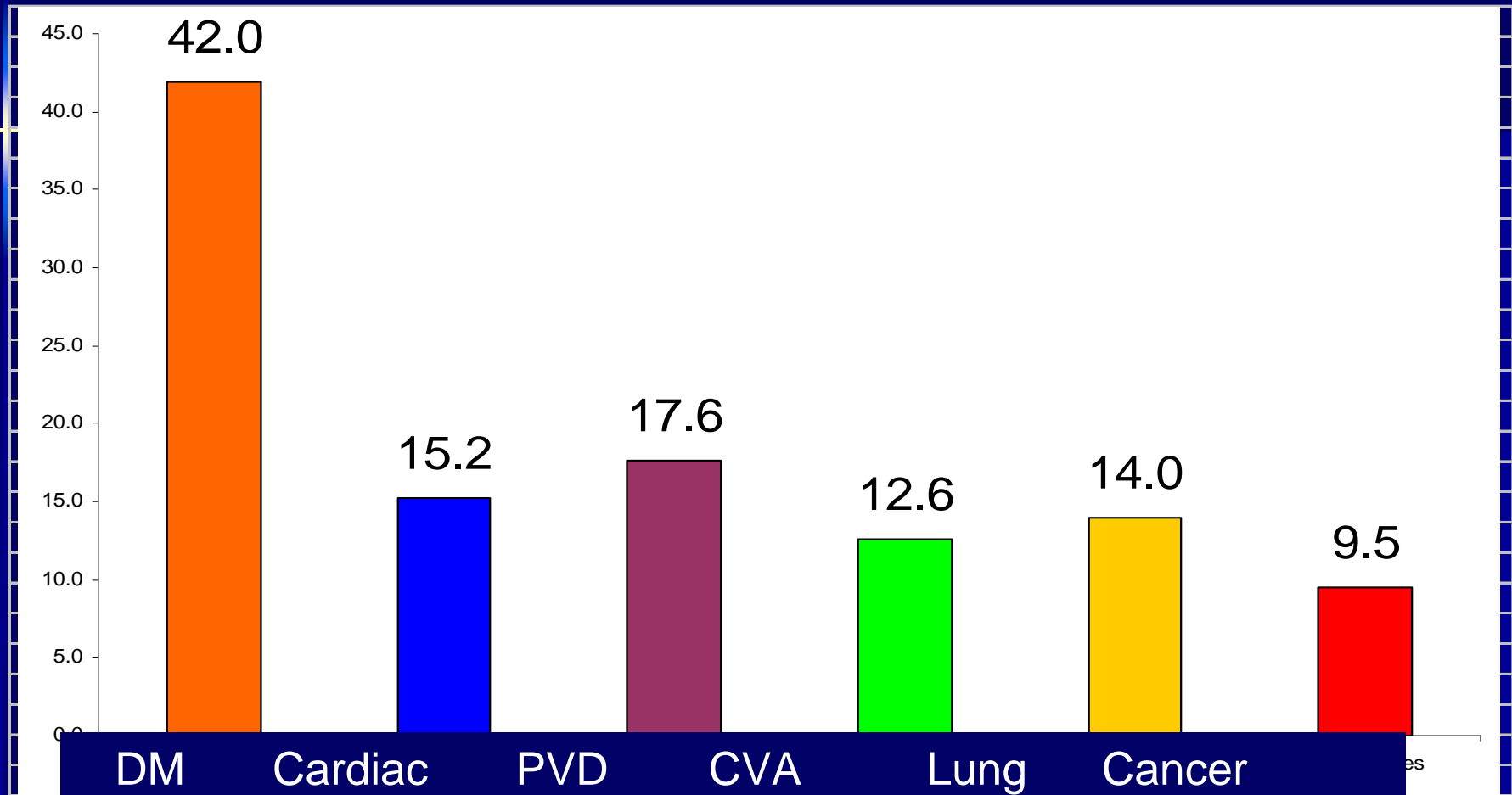
Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2006)

Prevalent ESRD Patients by Age Group, Canada, 1990-2004* (Age-specific Rates Per Million Population)



*Based on reported data , CORR, 2006

Selected Co-morbid conditions Incident ESRD Patients, Canada, 2004* (Percent)



*Based on reported data.

**Proportion of diabetic patients is based on primary diagnosis and co-morbid disease.

** Heart disease includes MI and CABG

Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2006)

Comorbidity in Elderly Dialysis

	65 – 74	65 – 74	>75	>75
	<u>1990 - 1994</u>	<u>1995 - 1999</u>	<u>1990 - 1994</u>	<u>1995 - 1999</u>
DM	30%	40%	20%	27%
Vascular	23%	31%	25%	30%
Cardiac	27%	32%	23%	33%
Neoplasia	9%	12%	13%	13%

Survival Of Elderly Dialysis Patients by Age and Vintage

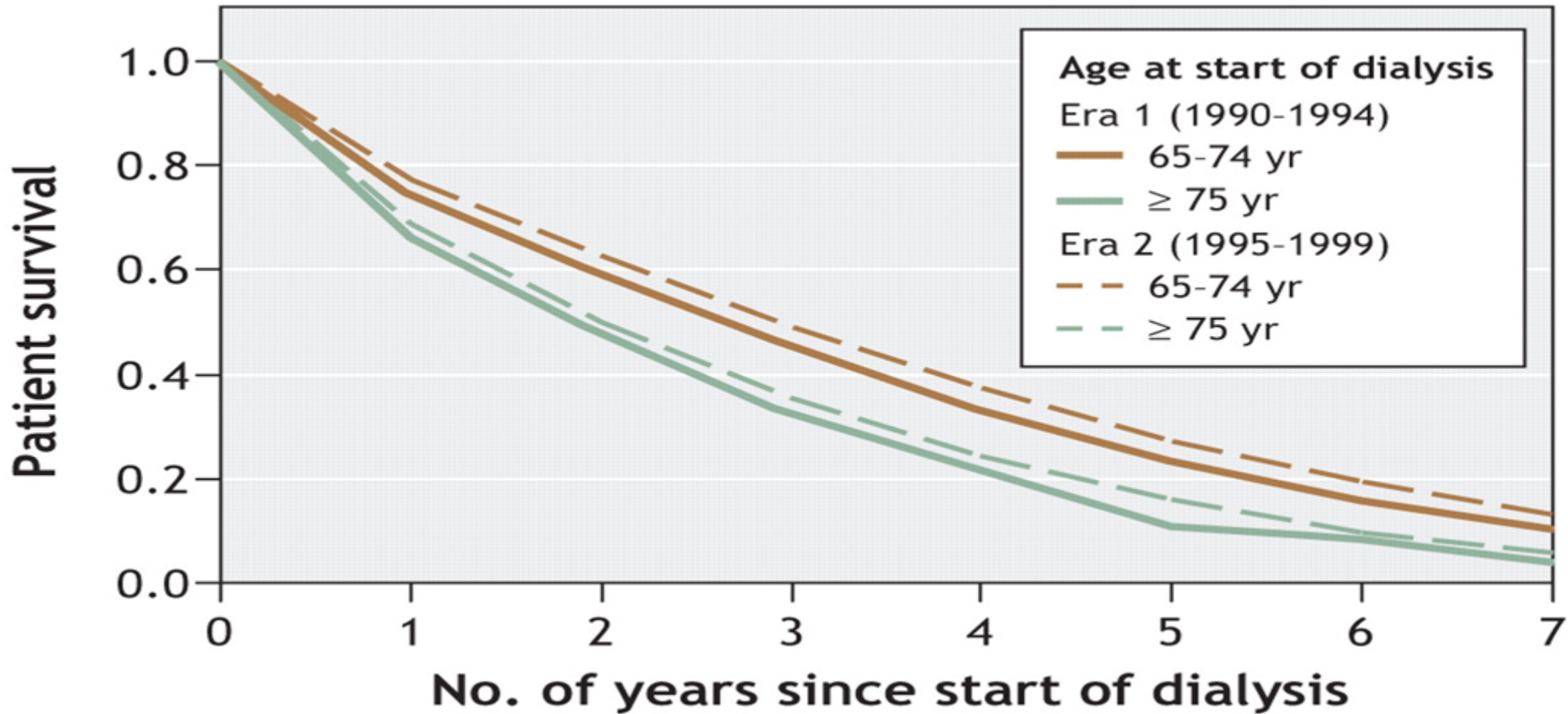


Table 2: Estimated life expectancy after dialysis initiation among 14 512 elderly patients, by study period

Age at onset of dialysis, yr	Study period; estimated life expectancy, mean (95% CI), yr	
	1990-1994	1995-1999
65-69	3.68 (3.59-3.78)	4.62 (4.55-4.69)
70-74	3.09 (3.00-3.18)	3.92 (3.85-3.98)
75-79	2.73 (2.63-2.83)	3.19 (3.03-3.35)
≥ 80	2.14 (2.03-2.25)	2.59 (2.51-2.67)

Note: CI = confidence interval.

CASE 1

■ CK

- 45 year old, single
- Renal disease secondary to GN as a teenager
- Dialysis commenced in 1975
- 3 previous transplants
- Back on dialysis for 6 years
- Warning signals
- Progressive dysphagia

Case 2

- Mr BD
 - 60 yo. Punjabi male
 - Renal failure, septic, gangrenous leg
 - Arrived in hospital directly from airport
 - 3 month hospitalisation:
 - Dialysis dependant
 - Bed bound
 - S.aureus endocarditis, not surgical candidate
 - BKA
 - Where to next

Case 3

■ Mr GW

- 80 year old male, diabetic hypertensive, CHF, IHD, mild CRF
- 3 hospitalisations in 3 months: CHF, EF 20%
- Cath – inoperable, ARF post cath and recovered
- Readmitted in pulmonary edema, intubated by EHS
- Now in ICU
- Not peeing – call Nephrology

Case 4

■ Mrs GL

- 88 yr old,
- Previously independent but had known DM, Cardiac history
- Acute on chronic renal failure
- Commenced on dialysis
- Functional deterioration
- Intermittently lucid
- Where do we go after three months in hospital

ESRD End-of-Life Demographics

- ❑ Rising median age of dialysis population
 - 48% > 65 yrs old
- ❑ Over 2600 dialysis patients die in Canada per year, 200 in BC.
- ❑ ~20% die after decision to withdraw
- ❑ High percentage with comorbidities
- ❑ High in-hospital death (61% in one study)
- ❑ Unknown but low % die with hospice/palliative care

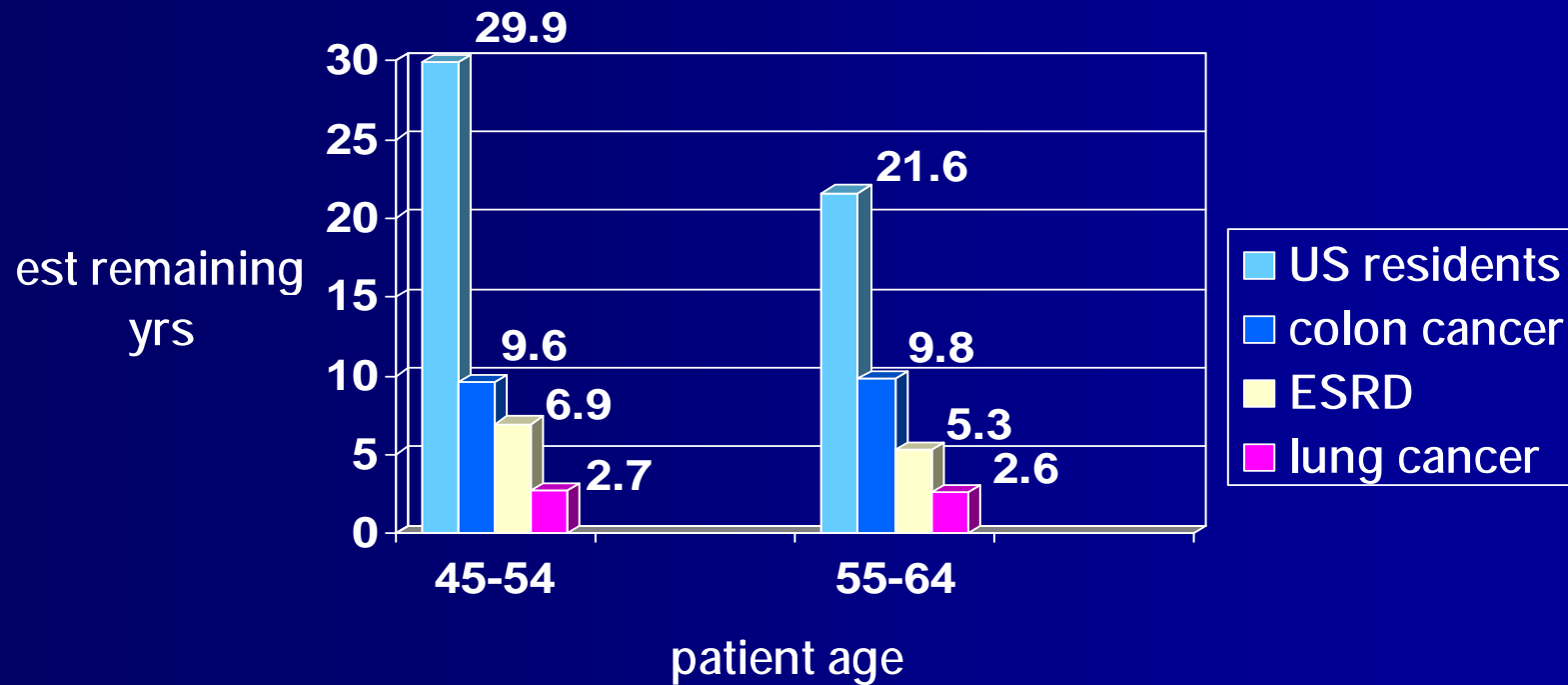
Why is it important for Nephrology

- ESRD 20 – 25% Mortality per year
 - Approx 75 - 100 deaths per year for Fraser valley program
 - Turnover 4 - times during working life
- In Canada withdrawal from dialysis now the second most common cause of death after CV disease and is cause of 20% of ESRD deaths
- How many of our patients are expected to die in the next year
- Quality of death – do patients die a “good” death

Expected Remaining Years of Life For 1996 Dialysis Populations

Age	Black Male	Black Female	White Male	White Female
20-24	16.8	15.9	14	13
30-34	12.7	12.5	9.4	9.3
40-44	10	9.8	6.9	7.1
50-54	7.3	7.1	5.2	5.2
60-64	5.2	5.3	3.7	3.9
70-74	3.5	3.7	2.7	2.9
85+	2.1	2	1.7	1.7

USRDS 1995 -- Life Expectancy Among Selected Chronic Diseases



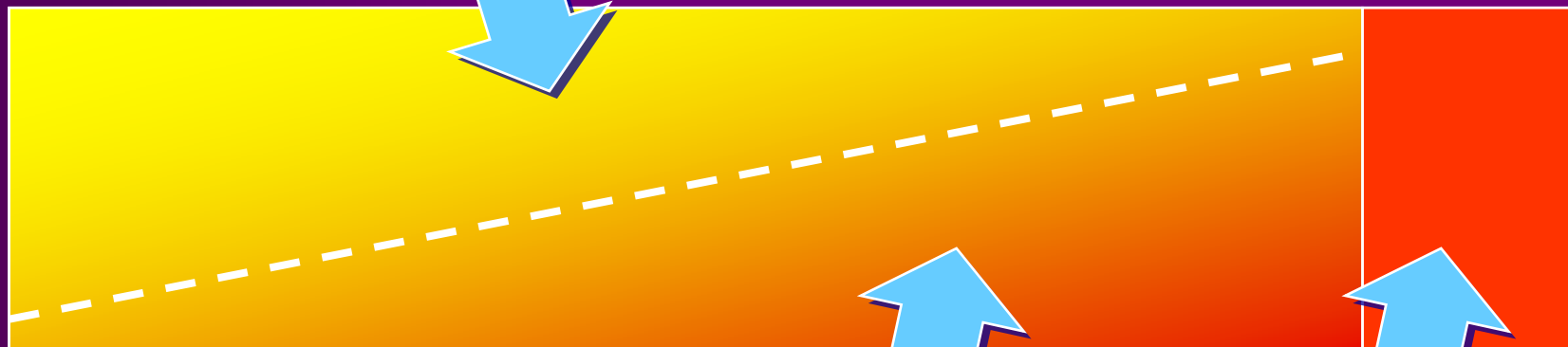
ESRD Patient Probability of Survival

Patient Population	Survival (%)
1-yr for all incident patients, unadjusted	79
1-yr for incident patients >65 yrs, unadjusted	65
2-yr for all incident patients, unadjusted	65
2-yr for all incident patients >65 yrs, unadj	48
5-yr for all incident patients, unadjusted	38
5-yr for incident patients >65 yrs, unadjusted	18
10-yr for all incident patients, unadjusted	20
10-yr for incident patients >65 yrs, unadjusted	3

Reasons for Withdrawal

- Unacceptable quality of life (failure to thrive)
- Acute complication
- Dementia
- Stroke
- Cancer
- Other

Curative / Remissive Therapy



Start Dialysis

Death

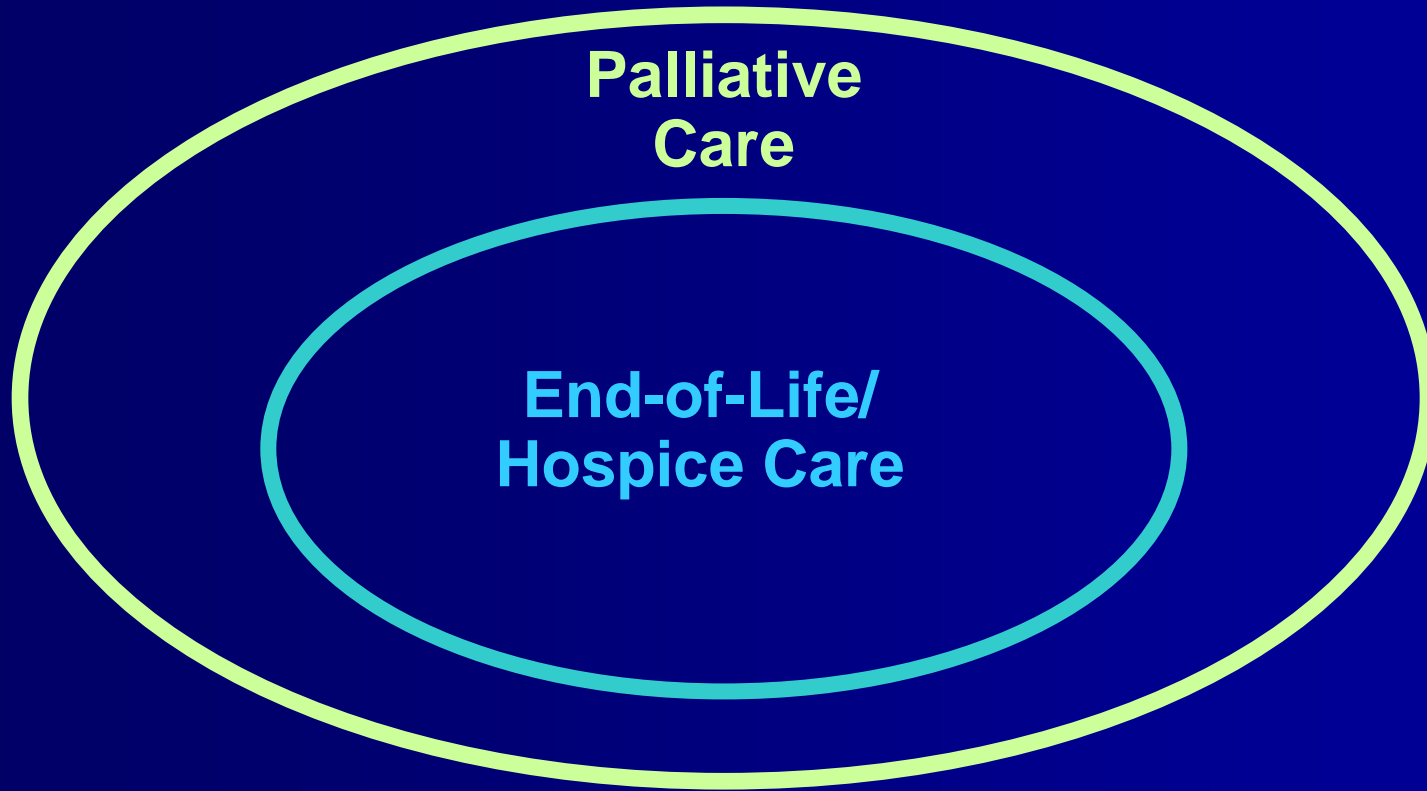


Palliative Care

Hospice

Would you be surprised if the patient died in the next year?

Palliative Care, Supportive Care and EOLC



Addressing Patient's Concerns Regarding End-of-Life Care Opportunities in Dialysis

- Receiving adequate pain and symptom control
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden on loved ones
- Strengthening relationships with loved ones

Singer PA, et al. Quality end-of-life care: patients' perspectives. *JAMA* 1999; 281:163-168.

Top 5 Attributes of a Good Death

- ❑ Freedom from pain
- ❑ At peace with God
- ❑ Presence of family
- ❑ Mental awareness
- ❑ Treatment choices followed

Steinhauser, et al. Factors considered important at the end of life by patients, family, physicians, and other health care providers. *JAMA* 2000;284:2476-2482.

Major Components of a Good Death

- ❑ Pain and symptom management
- ❑ Clear decision making
- ❑ Preparation for death
- ❑ Life Completion
- ❑ Contributing to others
- ❑ Affirmation of the whole person

Steinhauser. *Ann Intern Med* 2000;132:825-832.

What is the patients viewpoint?

- Patients are generally aware and state their preference to forgo life support if Prognosis and QOL is poor
- Patients are willing to discuss end of life issues but they are often waiting for staff to begin discussions
- Patients look to us for guidance
- Care providers often underestimate QOL – not necessarily related to functional status especially in elderly

Aspects of Palliative Care For Nephrology Programs

- Pain and symptom management
- Advance care planning
 - Establishing and reviewing Goals of Care
 - DNR
 - Advance Directives
- Psychosocial and spiritual support
- Hospice referral

RPA/ASN Statement on Quality Care at the End of Life

Recommendations

1. All members of the renal health care team including nephrologists, nephrology nurses, nephrology social workers, and renal dietitians should obtain **education and skills in the principles of palliative care** to ensure that ESRD patients and families receive multidimensional, compassionate, and competent care at the end of life.

RPA/ASN Statement on Quality Care at the End of Life

2. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to **determine, if possible, why the patient/surrogate has decided to forgo dialysis** ... Once the nephrologist is satisfied that the patient's decision to forgo dialysis is informed and uncoerced, the nephrologist should **respect the wishes of the patient/surrogate**.

RPA/ASN Statement on Quality Care at the End of Life

3. After a decision is made to forgo dialysis, the renal team should refer the patient to a hospice or adopt a palliative care approach to patient care. In either case, the nephrologist and other members of the renal team should remain active in the patient's care to maintain continuity of relationships and treatment.

RPA/ASN Statement on Quality Care at the End of Life

4. Nephrologists and other members of the renal team should obtain **education and skills in advance care planning** so that they are comfortable addressing end-of-life issues with their patients.

RPA/ASN Statement on Quality Care at the End of Life

5. Dialysis facilities should develop protocols, policies, and/or programs to ensure that advance care planning is conducted with their patients.

RPA/ASN Statement on Quality Care at the End of Life

6. Nephrologists should explicitly include in their advance care **planning...information about the outcomes of CPR for patients with ESRD and a discussion of patients' preferences regarding CPR** if cardiac arrest were to occur while patients are undergoing ...dialysis... The RPA/ASN encourages dialysis facilities to develop policies and procedures for respecting the wishes of dialysis patients with regard to CPR in ... the dialysis unit.

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



Recommendation #1: Shared Decision-Making

A patient-physician relationship that promotes **shared decision-making is recommended for all patients with either ARF or ESRD**. Participants in shared decision-making should involve at a minimum the patient and the physician. If a patient lacks decision-making capacity, decisions should involve the legal agent. With the patient's consent, shared decision-making may include family members or friends and other members of the renal care team.

Recommendation #2: Informed Consent or Refusal

Physicians should fully inform patients about their diagnosis, prognosis, and all treatment options, including:

1) available dialysis modalities,

2) not starting dialysis and continuing conservative management which should include end-of-life care,

1) a time-limited trial of dialysis, and

2) stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary...

Recommendation #3

Estimating Prognosis

To facilitate informed decisions about starting dialysis for either ARF or ESRD, discussions should occur with the patient or legal agent about life expectancy and quality of life....

All patients requiring dialysis should have their chances for survival estimated, with the realization that the ability to predict survival in the individual patient is difficult and imprecise. The estimates should be discussed with the patient or legal agent, patient's family, and among the medical team.

Predictors of Poor Prognosis for ESRD Patients

- Age
- Functional ability
- Nutritional status
- Comorbid Illnesses - diabetes, MI, PVD

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

Nutritional Status

- Serum albumin < 3.5 g/dL \approx 50% 1 yr mortality
- Serum albumin < 2.5 g/dL vs > 4.0 g/dL confers 7.45 greater risk of early death

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

Indicators of Poor Prognosis

- ❑ Severe functional impairment confers 3.46 times greater risk of early death
- ❑ Acute MI associated with 60% 1 yr mortality
- ❑ AKA associated with 73% 1 yr mortality

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

Table 8. 18-Month Survival for 1988 Prevalent Patients by Level of Albumin Concentration (Lowrie, 1990).¹⁵⁵

Average Albumin Concentration (g/dL)	N exposed	N Died	Risk of Death	RR to Index of 4.01-4.5
>4.5	124	10	0.0806	0.83
4.01-4.5	3,931	382	0.0972	1.00
3.51-4.0	6,517	1399	0.2147	2.21
3.01-3.5	1,266	598	0.4724	4.86
2.51-3.0	157	107	0.6815	7.01
≤2.5	29	21	0.7241	7.45

Table 9. Patient Functional Status and Mortality Among 10,355 Incident HD and PD Patients, Network 6, 1989 to 1991.¹⁶⁸

Functional Status	N	Mortality		
		%	Rate*	RR(95% CI)
Normal*	1,128	13.1	8.3	
Mildly Impaired	3,215	37.3	10.6	1.28(1.08-1.52)
Moderately Impaired	2,748	31.8	19.0	2.29(1.94-2.70)
Severely Impaired	1,538	17.8	28.7	3.46(2.93-4.10)

*Unadjusted mortality rate expressed as deaths per 100 dialysis years

†Reference Group

Charlson Comorbidity Index

1 point	MI, CHF, PVD, CVA, Dementia, COPD, PUD, Mild liver disease
2 points	Mod-severe CKD, CA w/o mets DM with end-organ damage
3 points	Mod-severe liver disease
6 points	Metastatic solid CA AIDS
1 point	Each decade in age > 40 years

Beddhu et al. Am J Med 2000;108:609-613

Prognosis from CCI

	Low score	Mod Score	High Score	Very High Score
CCI Points	< or =3	4-5	6-7	= or >8
Mortality (per pt-yr)	0.03	0.13	0.27	0.49

Who Should Not Be Dialyzed

- ❑ Patients (legal agents) who refuse dialysis
- ❑ Patients with profound neurological impairment
- ❑ Patients terminally ill from a non-renal cause
- ❑ Patients whose condition precludes the technical process of dialysis-advanced dementia and severe mental disability

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

Recommendation #8

Time-Limited Trials

For patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis, nephrologists should consider offering a time-limited trial of dialysis.

Recommendation #7

Special Patient Groups

It is reasonable to consider not initiating or withdrawing dialysis for patients with ARF or ESRD who have a terminal condition from a nonrenal cause or whose medical condition precludes the technical process of dialysis.

Recommendation #5

Advance Directives

The renal care team should attempt to obtain written advance directives from all dialysis patients. These advance directives should be honored.

Reasons to Dialyze Terminally Ill Patients

- Short-term benefit for competent patient
- Time-limited trial of dialysis to help patient and family understand burdens of treatment

End of life care in the dialysis unit

- What does it mean
- How does it change therapy
- Dialysis unit “culture”
 - Death denying/life saving
 - Attitudes of attending MD
 - Support of all staff
 - Involvement of all disciplines
 - Training
 - Ethnicity and religious background

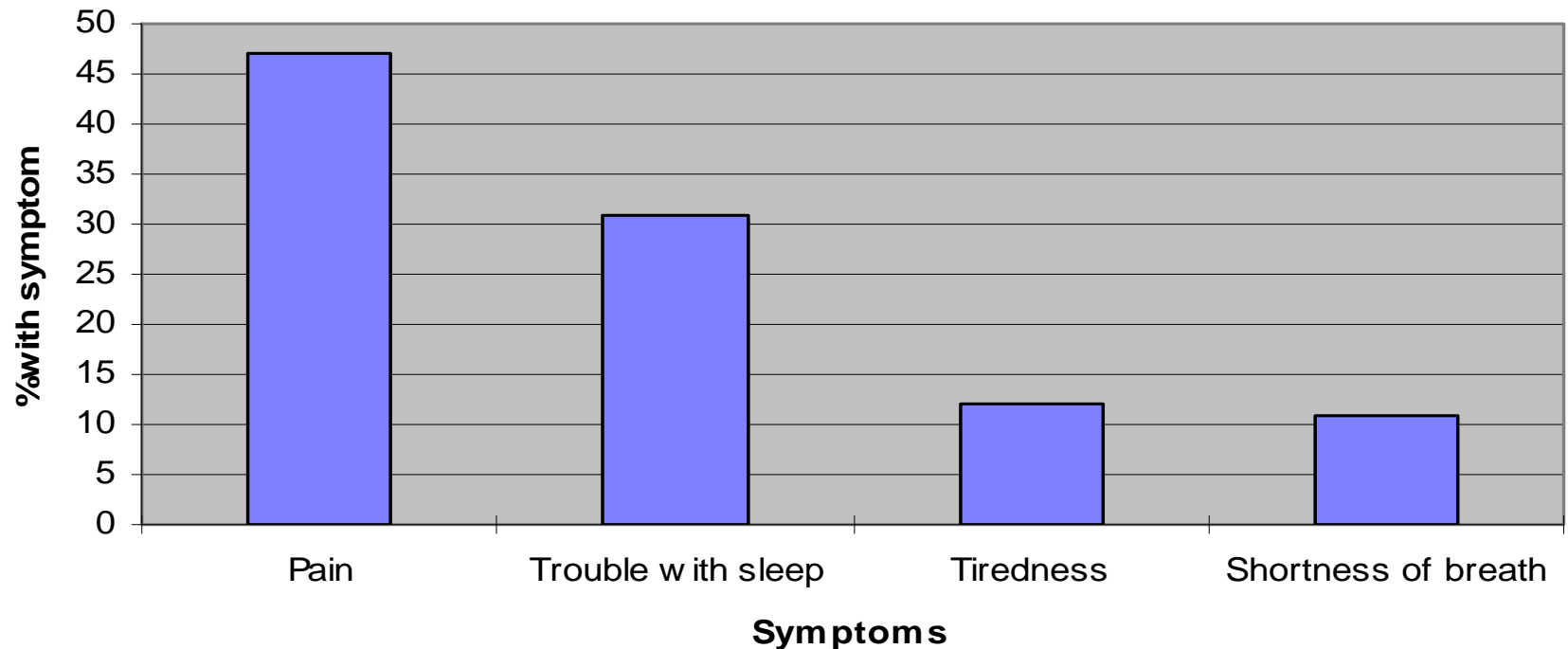
Components of a Renal Palliative Care Program

- ❑ A Palliative Care Focus
 - Educational activities (in-services)
 - QI activities (M & M conferences, Quality of Death)
 - “Would you be surprised...?”
- ❑ Pain & Sx Assessment & Management Protocols
- ❑ Systematized Advance Care Planning
 - Communication of prognosis and changes in condition
- ❑ Psychosocial and Spiritual Support (peer counselors)
- ❑ Terminal Care Protocol (includes hospice)
- ❑ Bereavement Program (includes memorial service)

Pain and Symptom Assessment and Management Protocols

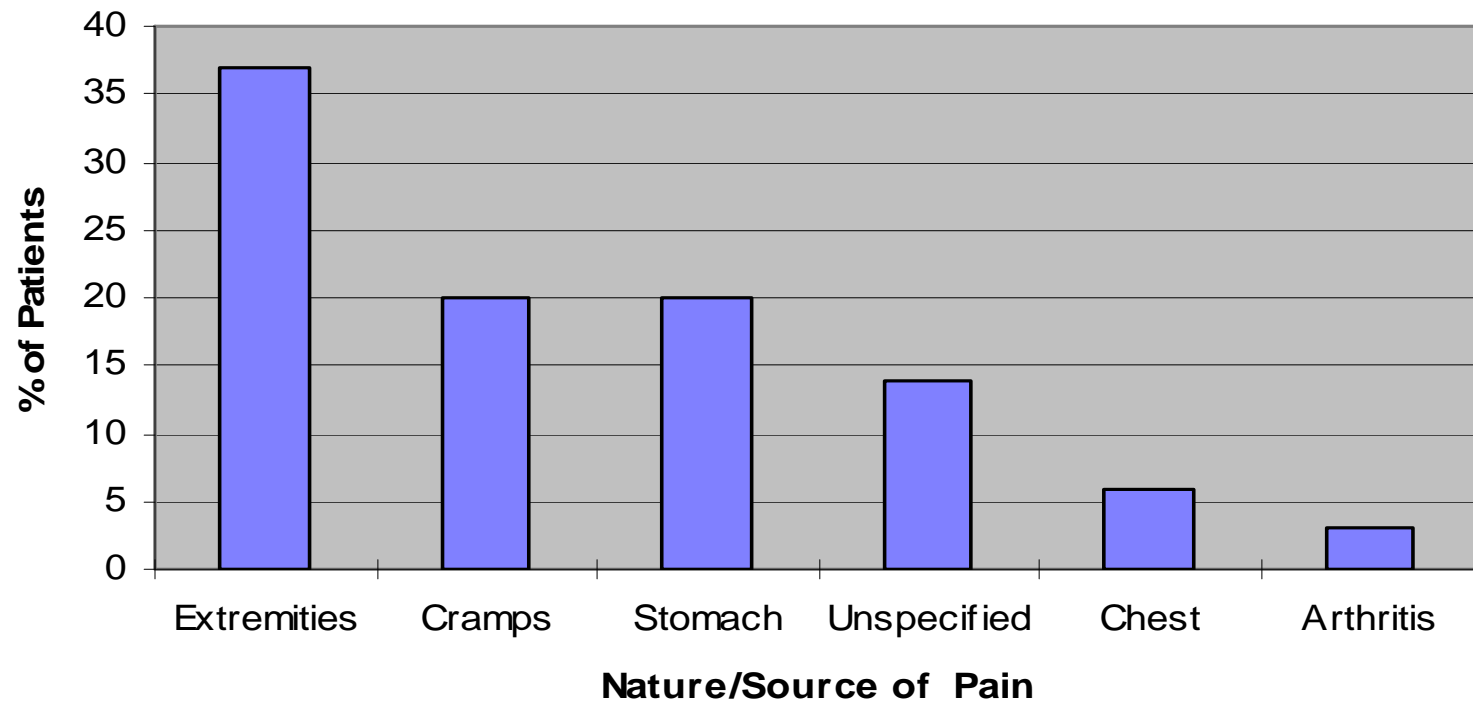
The Importance of Pain As a Symptom

Figure 2. Most Common Symptoms Reported by Symptomatic Patients



Types of Pain Reported

Figure 3. Source of Pain in Patients Reporting Pain



Advance Care Planning

RWJF ESRD Workgroup Recommendation: Advance Care Planning

Nephrologists should routinely invite patients to express their end-of-life care preferences in the required semi-annual short-term and annual long-term care planning meetings.

Why do advance care planning?

1. To be able to respect patients' wishes and treat them the way they want to be treated
2. Because there is a presumption in favor of continued dialysis for patients who cannot and have not expressed their wishes, patients' rights to forgo dialysis in certain situations are usually difficult to achieve unless patients have explicitly stated their preferences in advance or named a surrogate to speak on their behalf.

Why do advance care planning?

The usual practice of nephrologists in treating patients who have become incompetent and who have never provided either oral or written advance directives regarding their preferences for stopping dialysis is to continue dialysis.

Special Need for ACP in ESRD

- Large % of elderly who have more comorbid conditions and are more likely to withdraw from dialysis
- CPR is of very limited value
- ACP discussion helps reconcile patients and families to the end of life

Increasing the Completion of AD by Chronic Dialysis Patients

- **focus on health states, not interventions (Singer, Holley)**
- **involve surrogates in discussions (Moss, Singer, Holley, Swartz)**
- **increase dialysis unit staff's attention to and comfort with discussing advance directives (Perry, Holley)**

Would you be surprised if the patient died in the next year?

Clinical Indications for Discussing End-of-Life Care --Routine

- Deciding with trusted family/friend
- Respect of treatment preferences
- Discussing treatment with low probability of success
- Discussing prognosis
- Discussing hopes and fears

Clinical Indications for Discussing End-of-Life Care -- Urgent

- Imminent death
- Talk about wanting to die
- Inquiries about hospice or palliative care
- Recently hospitalized for severe progressive illness
- Severe suffering and poor prognosis

Representative Questions for End-of-Life Discussions

■ Goals –

- Given the severity of your illness, what is most important for you to achieve?
- What is most important to you in treatment for your illness?
- What are your biggest fears? What do you want to avoid in your treatment?
- What are your most important hopes?

Representative Questions for End-of-Life Discussions

■ Values

- What makes life most worth living for you?
- Are there any circumstances under which you would not find life worth living?
- What do you consider your quality of life to be like now?
- Have you seen or been with someone who had a particularly good (or difficult) death?

Conclusions

- completion of written AD was associated with better communication among patients and their designated decision makers
- placing ACP within the physician-patient relationship may be contributing to the failure of ACP -- a patient-centered, family-based model is more appropriate (only 36% of patients overall wanted to include a physician in ACP discussions)

Conclusions

- stopping dialysis is rarely considered in ACP by chronic hemodialysis patients (31% of those who had devoted the most attention to ACP, 8% of those who had not completed an AD)
- encouraging patients to consider circumstances in which they would want to stop dialysis should be part of ACP

Take-Home Message

Nephrologists need to encourage advance care planning to their patients and direct their dialysis unit social workers to assist the patient/family in the process. In the end, good advance care planning helps everyone.



Psychosocial and Spiritual Support

RWJF ESRD Workgroup Recommendation

CMS should require dialysis units to provide reasonable time for social workers to counsel patients on psychosocial issues surrounding end-of-life care. At present, social workers are not using their professional skills for psychosocial support of patients because they are given other roles such as arranging patient transportation. Others might perform these functions.

Terminal Care Protocol

Bereavement Program

Conclusions

- ❑ Because of shortened life expectancy, end-of-life care is particularly relevant for ESRD pts.
- ❑ Palliative care offers the treatment most pts and families want but is a new way of thinking.
- ❑ The knowledge and skills to provide palliative care for ESRD patients are available but not in widespread use.

Conclusions

- Pain and symptom management are directly related to dialysis patient QOL.
- Pain is the most troublesome symptom for dialysis patients.
- Advance care planning is necessary to respect dialysis patients' wishes, including for CPR.
- Psychosocial and spiritual support are key components of ESRD patient care.

Take-Home Message

Because of the nature of ESRD, **end-of-life care** needs to be part of the *continuum* of **quality** patient care for ESRD patients.



....we should hope to avoid being portrayed as "physicians so preoccupied with the preservation of life that they can no longer see the broader human context of their work, physicians who have lost sight of one of the privileges and responsibilities of medicine: to offer some humanity at moments of suffering and loss" [25].

Octogenarians Reaching End-Stage Renal Disease: Cohort Study of Decision-Making and Clinical Outcomes

JASN 14: 1012 – 1021 2003

- Study Design:
 - 146 consecutive Octogenarians referred for ESRD care
 - 107 Offered dialysis
 - 37 Offered conservative care
- Results
 - Median Survival: 29 vs 9 months
 - Predictors of death within one year of dialysis:
 - Poor nutritional Status
 - Late referral
 - Functional Dependence
 - Predictors beyond one year
 - Peripheral Vascular disease

Old age is like flying through a storm. Once you're aboard, there's nothing you can do.

~ Golda Meir ~

Cause of Death in elderly dialysis

Cause of Death	Percent
Withdrawal	38
Infection	22
Cardiovascular	24
Malignancy	7
CVA	5
COPD	2
Neurological	2

Dialysis vs. Conservative Management of Elderly Stage 5 CKD Patients

- Murtagh et al NDT 2007: (22) 1955
 - Retrospective review of 129 CKD patients > 75
 - 4 UK Renal Units
 - GFR > 15 mls/min
 - Endpoint: Survival from GFR < 15 to death
 - 52 elected to start HD
 - 77 chose Conservative treatment

Dialysis vs. Conservative Management of Elderly Stage 5 CKD Patients

Murtagh et al NDT 2007: (22) 1955

- Conservative vs. Dialysis
 - No difference in Co-morbidity
 - Age: 83 yrs (c) vs 79.6 (D)
 - 1 year survival
 - 84% (D)
 - 68% (c)
 - 2 yr Survival
 - 76% (D)
 - 47% ©
 - But no difference in those with Ischemic Heart Disease

Conservative care of CKD in elderly

- Out of 175 patients over the age of 75, median survival was 33 months among 128 patients who underwent dialysis compared with 22 months in those who chose maximal conservative management
- Appears to be significant differences in hospital-intervention-free days
- 80% of the conservative-management group died at home or in a hospice environment, whereas 80% of the dialysis group died in the hospital.
- When patients chose a maximum conservative pathway, they also start talking about where they want to die and make plans to die in one of the surrounding hospices or have hospice service at home.
- Patients who chose maximal conservative management remain functionally stable till very close to the end of life.

What do Patients choose

- 84% of the subjects would choose dialysis treatment,
- 78% of all elderly would attend hospital as necessary, if their symptoms could be relieved.
- 54% of the in-patient elderly and 83.3% of nursing home elderly even when physically disabled and living in a nursing home would want dialysis for end-stage renal failure.
- 74% of all elderly preferred to have home dialysis treatment.
- Only 36% of the subjects thought cost was important when allocating dialysis to the elderly.
- Being independent and free from major symptoms was regarded as important for a good quality of life.
- *Conclusions:* In this survey, elderly subjects wanted dialysis treatment. Neither age nor cost were considered important determinants for resource allocation. Symptom relief and maintaining independence were considered the main goals of treatment.