What is new in Renal Supportive Care ?

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Renal Supportive Care Symposium 2013, St George Hospital.

1. ANZSN Renal Supportive Care Position Statement and Guidelines (2013)

2. International and national developments

3. Development of Curricula in Renal Supportive Care for Doctors, Nurses and Allied Health.

ANZSN Renal Supportive Care Position Statement and Guidelines

Nephrology 2013; 18; 393 - 454

While it follows other work internationally it is very specific to the particular issues in Australasia.

RPA Clinical Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis (2nd ed. 2010).

Working group :

Representatives of multiple disciplines including Nephrology, Renal Nursing, Palliative Medicine, General Practice, Medical Law, Central Australia Renal Services (Alice Springs) and Department of Maori Health.

Conveners of the Working Group:

- Susan Crail, Nephrologist, Adelaide.
- Mark Brown, Nephrologist, Sydney

The often difficult decision of which patients will benefit from dialysis

“Perhaps the most difficult decision facing nephrologists today is that of ‘selecting’ which patients will benefit from dialysis in an overall patient centred sense, not just in terms of days survived or achievement of target Hb, Phosphate, Kt/V or other outcomes.”

This represents a subtle shift in language to previous Australasian guidelines

Ethical Considerations

The cardinal factor for acceptance onto dialysis or continuation of dialysis is whether dialysis is likely to be of benefit.

CARI guidelines – Ethical Considerations

A useful starting point for recommending dialysis is an expectation of survival with a quality of life acceptable to the patient.

CARI guidelines – Ethical Considerations

- Benefit – survival, acceptable QOL

- Benefit – “overall patient-centred sense”

“The overall aim is to help direct patients and their families so as to encourage those who will benefit most from dialysis to have this while being honest and direct with those who are unlikely to benefit or even be harmed by dialysis.”

The reference to the latter group is immediately linked to the conservative management of ESKD :

“Consequently it is imperative that we have mechanisms in place that support those who do not receive dialysis in such a way that they have good symptom control and quality of life.”

“Key principles” to assist Nephrologists in these discussions :

1. Nephrologists need to lead these discussions

2. Nephrologists need to have realistic discussions about likely patient survival on dialysis.

What do we know about survival ?

DIALYSIS

For patients on dialysis 13% mortality rate.
(ANZDATA Registry 2011 Report)

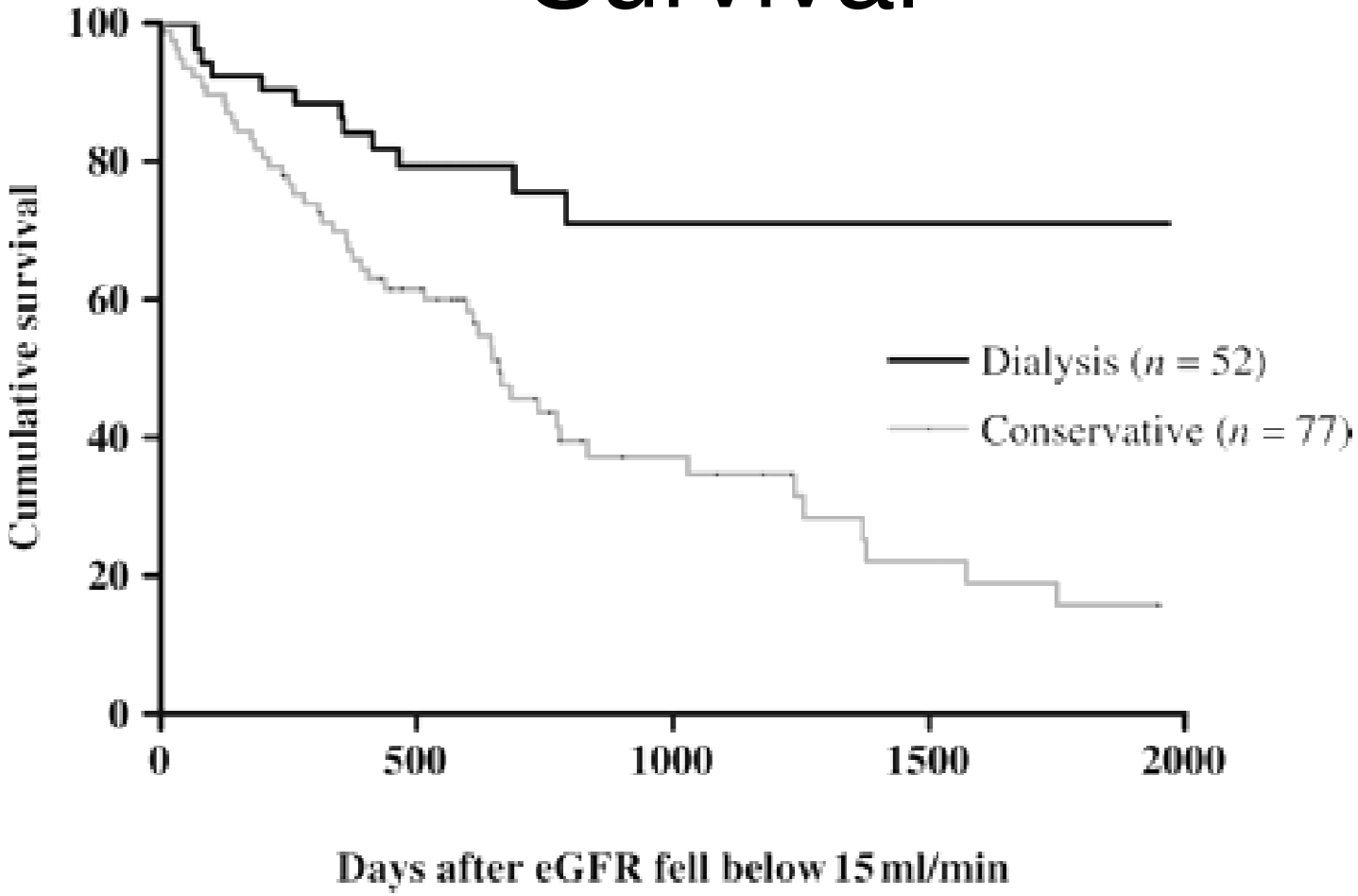
For those aged 75-84 years that figure is 20 % in the first year.

Survivorship and co-morbidity

Dialysis or not ? A comparative study of survival of patients over 75 years with CKD Stage 5.

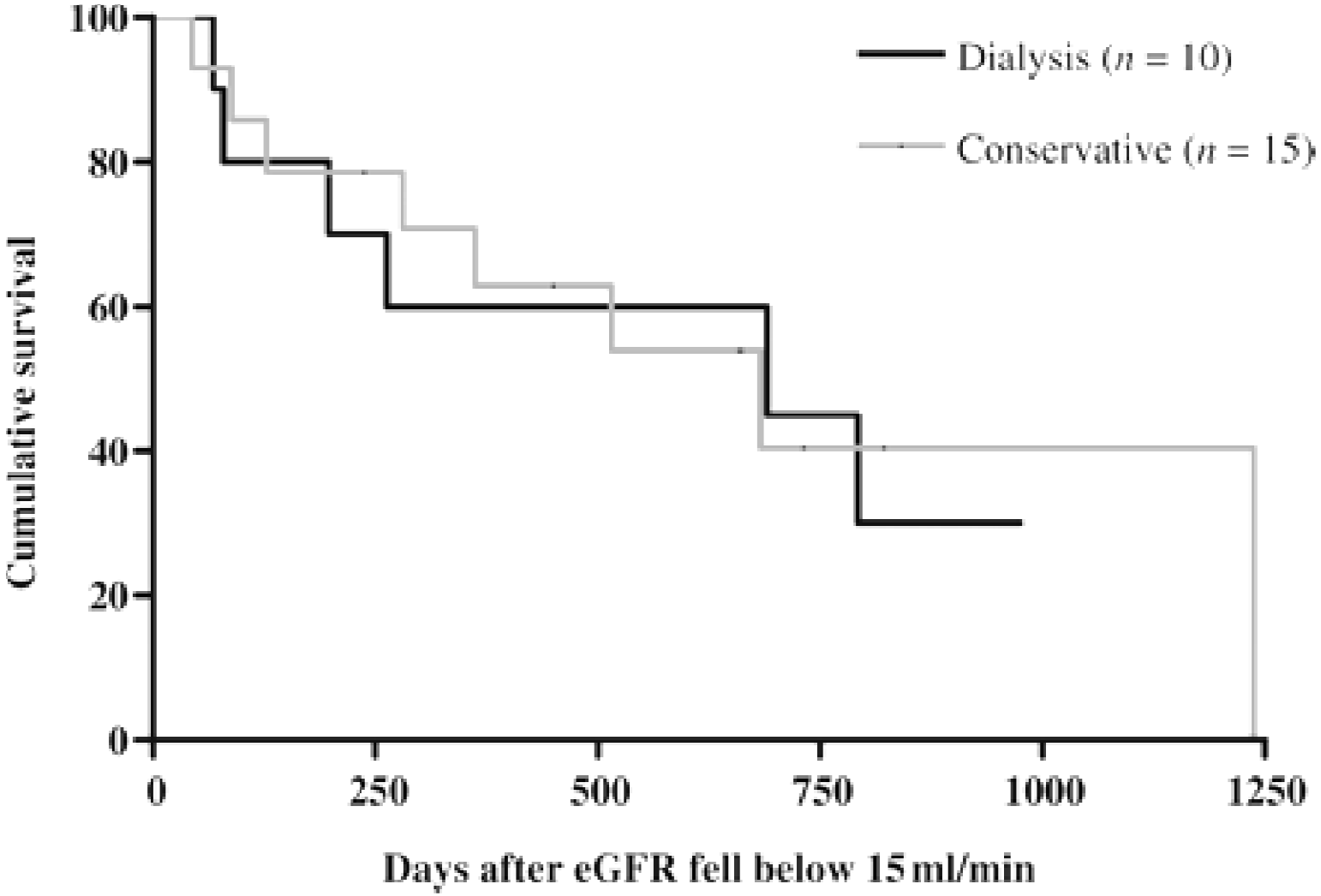
Murtagh FEM et al. *Neprol Dial Transplant* 2007;22:1955-1962

Survival



Murtagh et al. NDT. 2007;22:1955-62

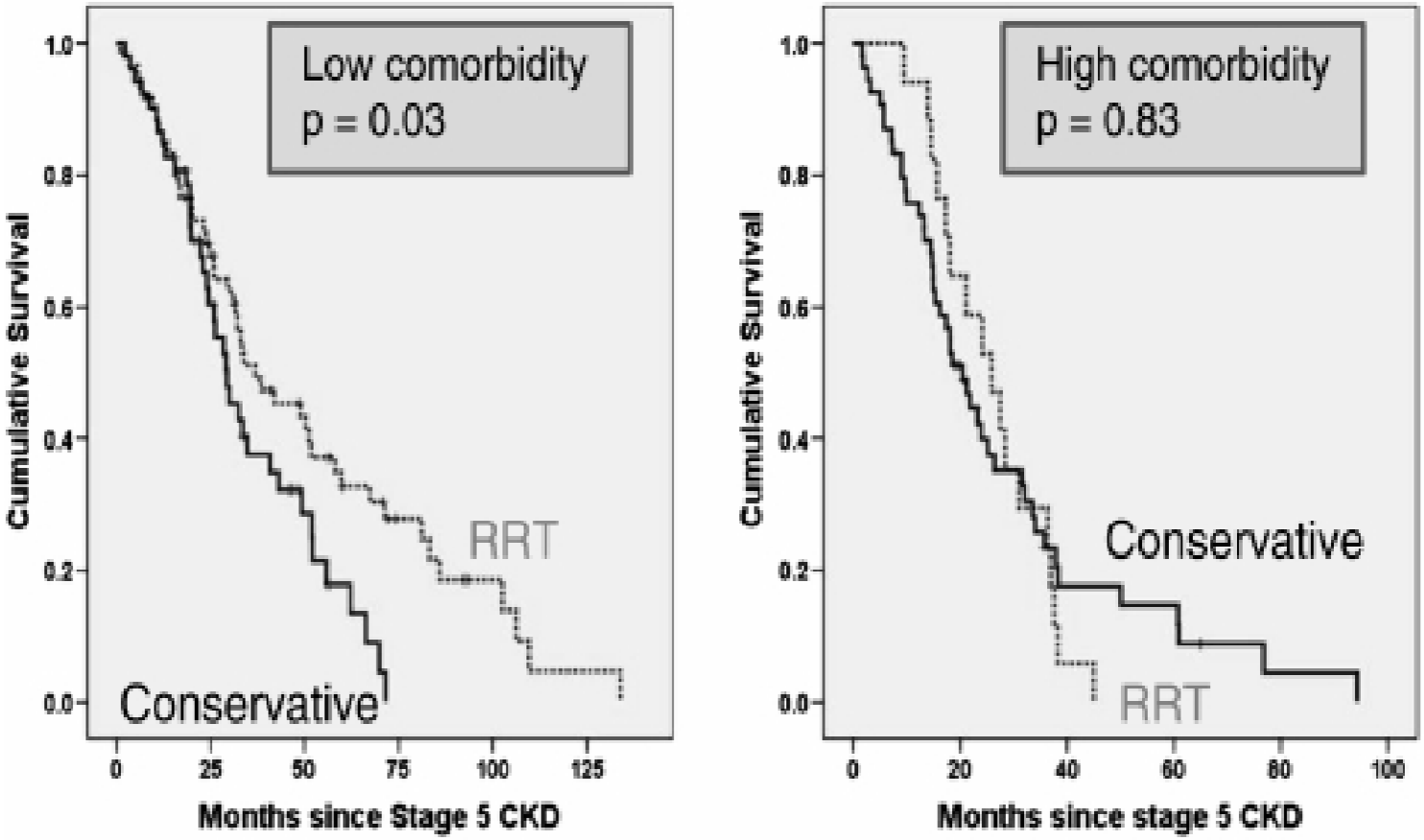
Survival benefit lost if Co-morbidities include IHD



Murtagh et al. NDT. 2007;22:1955-62

RRT v Conservative

Chandra et al NDT Nov 2010



3. Nephrologists need to have realistic discussions about QOL on dialysis

4. Nephrologists can be assisted in this decision-making process by applying the 4 Bioethical principles

5. Predictive models are available

RPA Clinical Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis (2nd ed. 2010).

Frank Brennan
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Renal Department Meeting October 28 2010

Recommendation No. 6

It is reasonable to consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis…

Stage 5 CKD who are over 75 years with 2 or more of the following statistically significant criteria predictive of very poor prognosis :

(a) Surprise question.
(b) High Co-morbidity Score
(c) Significantly impaired Functional status
(d) Severe chronic malnutrition

The ANZSN Guidelines adds a 6th factor to consider – if the patient is a resident in a Nursing Home.

Dialysis in Frail Elders — A Role for Palliative Care

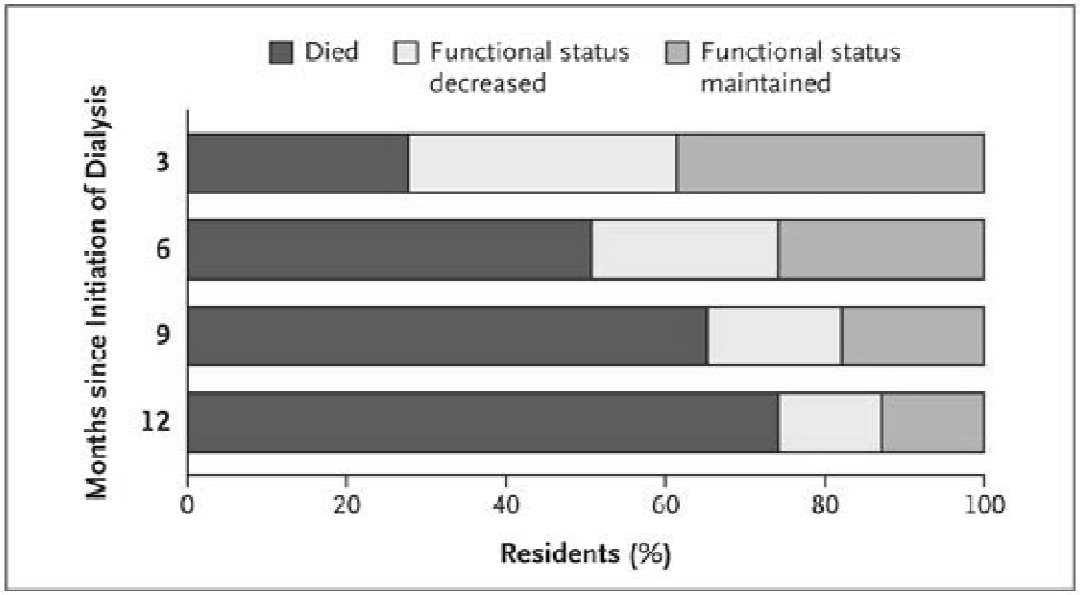
Robert M. Arnold, M.D., and Mark L. Zeidel, M.D.

The NEW ENGLAND JOURNAL of MEDICINE

Volume 361:1597-1598 **October 15, 2009**

Change in Functional Status after Initiation of Dialysis

3702 Nursing home residents mean age 73
Mean eGFR 10
Female 60%
Diabetes 68%
CHF 66%
CHD 44%
Cerebrovascular dis. 39%
Depression 35%
Dementia 22%

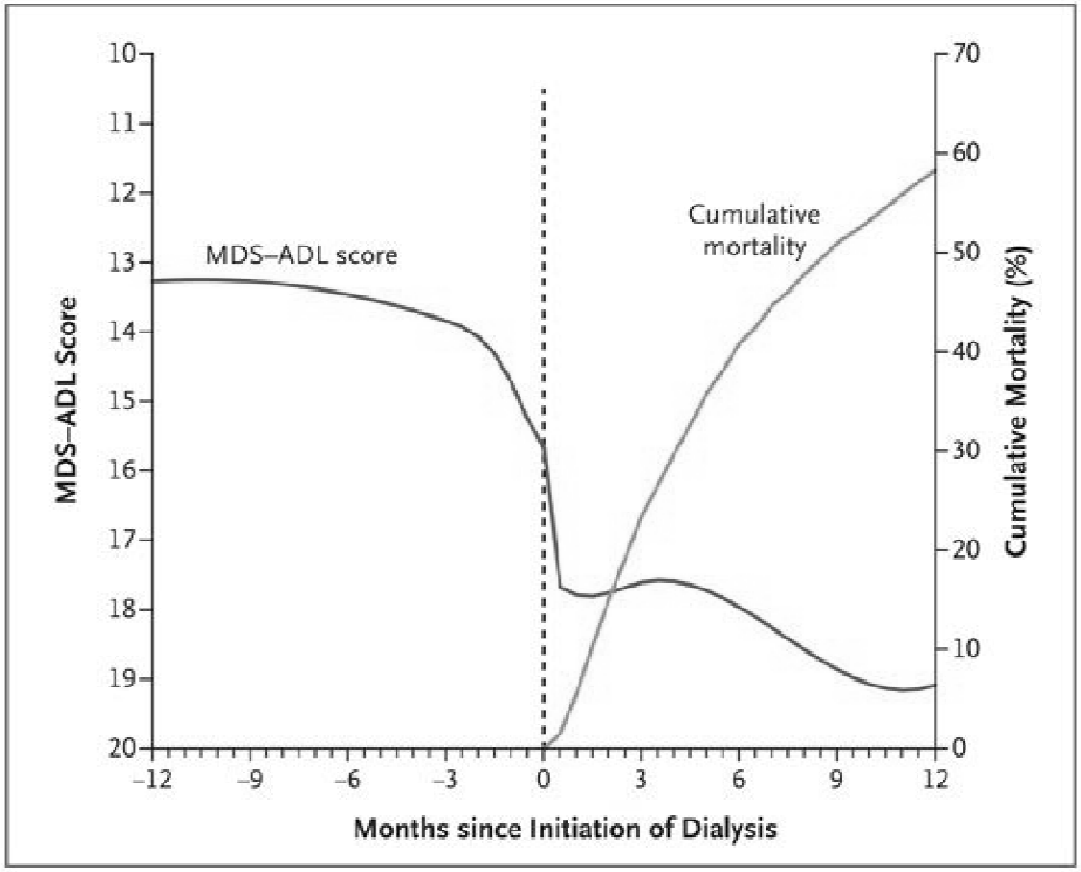


Kurella Tamura et al. 361 (16): 1539, October 15, 2009

The NEW ENGLAND JOURNAL of MEDICINE

Smoothed Trajectory of Functional Status before and after the Initiation of Dialysis and Cumulative Mortality Rate

[Nursing home residents mean age 73]



Kurella Tamura et al. 361 (16): 1539. October 15, 2009

The NEW ENGLAND JOURNAL of MEDICINE

6. Nephrologists need to ensure patient expectations about dialysis are realistic.

7. Nephrologists should guide the decision

“not just leave the patient and the family with a host of information and ask for a decision; many elderly patients are relieved to learn that dialysis is not compulsory.”

- “[M]any elderly patients are relieved to learn that dialysis is not compulsory.”

- “They do not lose hope in life by having these discussions; in fact the opposite is true.”

8. If a decision for a conservative pathway is made :

“it is imperative that the patient and family are informed about the positive things that can be put in place, ideally through a Renal Supportive Care programme…”

The conservatively managed patient should

"continue to attend all their usual nephrology appointments having standard ERKD medical therapies but have additional Renal Supportive Care, ensuring that they do not feel abandoned if choosing a non-dialysis pathway."

9. Dialysis patients should also “have the access to the management of burdensome symptoms.”

Perspective- The Issues Surrounding End Stage Kidney Disease and Dialysis in the Elderly and Those with Co-morbidities

Increasing numbers of elderly patients presenting with ESKD.

Does everyone who has ESKD commence dialysis ?

In Australia, for every one patient with ESKD receiving RRT

there is another who does not receive RRT

Australian Institute of Health and Welfare Research, June 2011

The mean age of commencement on Renal Replacement Therapy is 60.4 years (ANZDATA Registry 2009 Report)

In the USA the mean age of commencement is 65 years.

The age cohort that has the greatest prevalence is the 65-84 year old group.

What do we know about this group of patients ?

Considerable co-morbid burden

Of patients 75 years and over commencing dialysis 91 % had at least one co-morbidity and almost half had three or more co-morbidities.

Two thirds had IHD

One third PVD

One quarter Cerebrovascular disease.

Foote C et al. *Nephrol Dial Transplant* 2012;27:794-797.

- Survivorship
- QOL
- Hospital-free survivorship

Hospital-free survivorship

Elderly HD patients spend 50 % of their survival time on HD or in hospital with complications.

Carson RC et al. *Clin J Am Soc Nephrol* 2009;4:1611-1619.

Predictive Modelling Risk Calculators and the Non-Dialysis Pathway

Careful examination of the predictive models

Recommendations :

For CKD 3-5

The JAMA Kidney Failure Risk Equation

Demographic information, laboratory markers of CKD to predict which patients with CKD 3 to 5 will progress to the need for dialysis.

For patients being considered for a conservative pathway(particularly the elderly) :

1. Cochoud score – 9 risk factors.
2. Surprise Question

For dialysis patients being considered for a transition to conservative pathway(particularly the elderly with co-morbidities) :

1. Surprise question.
2. Modified Charlson co-morbidity score
3. Clinical score by Cohen et al.

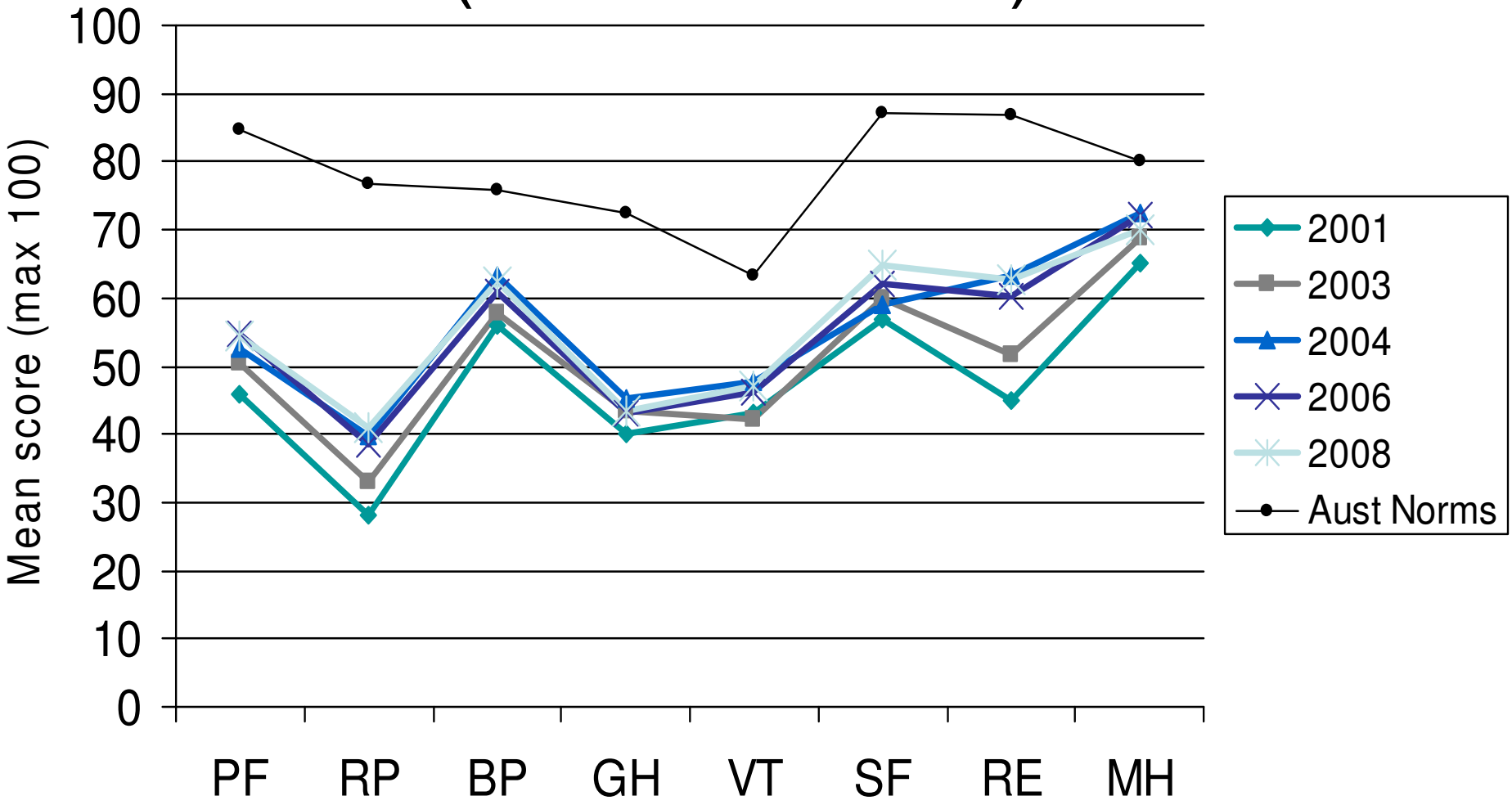
Quality of Life. What Information Is Already Available and What Evidence Is It Based On ?

Patients with ESKD on dialysis have a worse QOL compared to an aged matched general population

QOL is highly personal – what constitutes a poor QOL varies from person to person and the potential impact of dialysis on an individual will be unique to each person.

The SF-36 QOL survey tool is a suitable instrument

QOL - St George dialysis (SF-36 Scores)



Ethical principles for Patients, Families and Doctors to Consider

The ethical approach to decision making in whether or not to commence dialysis requires a careful weighing up of benefit and burden.

Employing the bioethical principles

“I want dialysis.. You must give it to me.”

Autonomy does not override the other principles.

There is no ethical obligation to offer dialysis to all patients

Competent patients, fully informed and acting voluntarily can refuse dialysis or request dialysis be discontinued.

There is clear and accepted ethical and legal principle that a competent patient has the right to refuse medical treatment.

The incompetent patients who had, when competent, expressed a wish to refuse dialysis…

Advance care plan.

The incompetent patient whose properly appointed surrogate medical decision-maker refuses dialysis or requests that it is discontinued.

In difficult cases Nephrologists should seek the advice of colleagues and, where available, a Bioethicist

Advance Care Planning

The rationale behind ACP

- An 82 y.o. man
- Ischaemic nephrosclerosis
- On HD for 2 years.
- Sudden collapse at home
- Significant CVA
- Barely rouseable – not able to make decisions

- Dialysis is due today
- Clinicians and family meet.
- Discussion about options…has the situation of him being too ill to make decisions been raised before ?
- “No, we’ve never talked about it.”

- Patient is incompetent
- No knowledge of patients wishes

- Clinicians may frame the discussion to family… “We have several options …what would like us to do ?”

- Places a significant burden on family.

Barriers to ACP

Patient/Family :

- May not be aware of the serious nature of their illness.
- May wait for clinicians to raise the topic.
- May perceive ACP as simply a way of cost cutting

Barriers to ACP

Clinicians :

- Thought to be too emotionally draining
- That raising these issues removes hope.
- No training in having these conversations
- That this is simply too time consuming.

- Timing
- Documentation
- Review

Appropriate Assessment of Symptom Burden and Provision of Patient Information

What symptoms are experienced by patients with ESKD ?

The Prevalence of Symptoms in End-stage Renal Disease : A systematic Review

Murtagh FE et al. *Advances in Chronic Kidney Disease*
Vol 14, No 1 (January) 2007; pp 82-99

A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis

Murtagh FEM et al. J Pall Med (2007) 10;6:1266-1276

SYMPTOM PREVALENCE

	Dialysis	Conservative
FATIGUE/TIREDNESS	71%	75%
PRURITUS	55%	74%
CONSTIPATION	53%	
ANOREXIA	49%	47%
PAIN	47%	53%
SLEEP DISTURBANCE	44%	42%

SYMPTOM PREVALENCE

	Dialysis	Conservative
ANXIETY	38 %	
DYSPNEA	35 %	61 %
NAUSEA	33 %	
RESTLESS LEGS	30 %	48 %
DEPRESSION	27 %	

The Guidelines gives recommendations for the management of individual symptoms

Holistic Palliative Care Approach – Physical, Spiritual, Religious and Psychosocial Needs

Inappropriate Interventions in the Dying Patient

A core competency of Nephrology should be the capacity to diagnose dying.

"That competency should also include its corollary – to consider the withdrawing of active medical care such as antibiotics, ionotropes, parenteral feeding and, ultimately, dialysis itself. *Failure to do this or procrastination in this process of recognition may result in neither the clinicians nor the family being prepared for the possibility of death.* That unpreparedness may have a significant impact on the bereavement of the family."

Running and Setting Up a Renal Supportive Care Programme

Models of Care – End of Life Pathways

Cultural Considerations When Providing Care to Aboriginal and Torres Strait Islanders Opting for Conservative Care

Cultural Considerations When Providing Care to New Zealand Maori Opting for Conservative Care

Issues and Models of Renal Supportive Care in Rural Areas

Renal Supportive Care and the Primary Physician

Research Issues in Elderly Patients : Gaps in Knowledge and Suggested Directions

Management Guidelines for Patients Choosing the Renal Supportive Care Pathway : Information and Web-based Treatment Protocols Available to All

Legal Issues concerning withholding and withdrawing from dialysis

Withholding or withdrawing from dialysis is not Euthanasia or Physician-Assisted Suicide

Survey of ACP and other relevant laws in all jurisdictions in Australia and New Zealand

Educational Needs in Supportive and End-of-Life Care

Case Vignettes

International developments

KDIGO Meeting on
Renal Supportive Care

UK

Formation of a UK Renal Palliative and Supportive Care Network

Launched at the British Renal Society Conference in 2012

Newsletter

renalpallnetwork@kcl.ac.ak

UK

Conservative Care for ESKD Medical Conference (2012)

Joint medical conference with :

The Renal Association of the UK

British Geriatrics Society and the

UK Association of Palliative Medicine

Inaugural National Symposium on Pruritus

- including Uraemic Pruritus

Development of Curricula in Renal Supportive Care for Doctors, Nurses and Allied Health.

Key publications

The last few years has seen a critical mass of literature in this area synthesising both the available evidence and expert opinion.

Chambers EJ, Germain M, Brown E (eds)

Supportive Care for the Renal Patient

2nd edition, 2010

Oxford University Press

End of Life Care in Nephrology

- **From Advanced Disease to Bereavement**

- Eds Brown, Murtagh

- Oxford Specialist Handbook, 2012

United Kingdom National Framework for the Implementation of End of Life Care in Advanced Kidney Disease

2009

RPA Clinical Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis (2nd ed. 2010).

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- Each of those publications point out gaps in our knowledge and the need for more research.

- Each highlight the need for education across multiple disciplines and a breadth and flexibility of perspective in practice.